

Consumer Outcomes

Phase VII Final Report
Fiscal Year 2004-2005 Data



A Collaboration of the
National Association of State Directors of Developmental Disabilities Services
and Human Services Research Institute

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I. Organization of Report

This document serves as the **final** report for the consumer outcomes portion of **Phase VII (2004-2005)** National Core Indicators (NCI) data collection. All consumer survey data submitted between **July 2004** and **June 2005** are included in this report. **A total of fifteen states plus Orange County are included in this final report.**

In addition, **Phase VII** consumer employment data is included.¹ The report is organized as follows:

INTRODUCTION -- Gives a brief overview of NCI activities to date, and presents the core indicators measured with the Consumer Survey and with the optional Day/Vocational/Educational Support supplement.

CONSUMER SURVEY -- Briefly describes the development and structure of the survey instrument.²

METHODS -- Describes the protocol for administering NCI consumer surveys, including sampling criteria, administration guidelines, and interviewer training procedures.

DATA ANALYSIS -- Explains the statistical methods used to analyze the consumer survey data. Includes an explanation of how certain outcomes are “adjusted” for the purposes of making comparisons across states. Also discusses scale construction and significance testing of results.

RESULTS: DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS -- Presents aggregate and state-by-state results of demographic information used for outcome adjustment.

RESULTS: CORE INDICATOR COMPARISONS ACROSS STATES -- Presents aggregate and state-by-state results for each question.

APPENDICES -- Include additional analysis information, services and supports received, and detailed item-by-item results.

¹ Most states collected consumer employment data by using the “Day/Vocational/Educational Support” Supplement to the Consumer Survey. In some states, however, these data are collected from providers on a regular basis and maintained in state data systems.

² For a detailed review of psychometric properties of the survey, including results of reliability and validity tests and features designed to test for consistency of responses, please see the NCI Phase II Technical Report.

II. Introduction

Overview of NCI

In December 1996, the NASDDDS Board of Directors launched the Core Indicators Project (CIP). The aim of CIP was to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that would enable them to measure service delivery system performance. This effort, now called National Core Indicators or NCI, strives to provide SDDAs with sound tools in support of their efforts to improve system performance and thereby to better serve people with developmental disabilities and their families. The Association's active sponsorship of NCI facilitates states pooling their knowledge, expertise and resources in this endeavor.

NCI Phase I began in January 1997. In August 1997, the Phase I Steering Committee selected a "candidate" set of 61 performance/outcome indicators in order to test their utility/feasibility. Six states agreed to conduct a field test of these indicators, including administering the NCI consumer and family surveys and compiling other data. Field test data were transmitted to NCI staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

NCI Phase II was launched in January 1999. Phase II data collection wrapped up in June 2000 and set the stage for continuation and further expansion of the NCI. During Phase II, the Phase I indicators were revised, and data collection tools and methods were improved. The Version 2.0 indicator set consisted of 60 performance and outcome indicators. Going forward, NCI expanded its scope to include services for children with developmental disabilities and their families, continued to develop and refine the indicators, and recruited additional states to participate in the collaboration. Phase II data are considered baseline NCI data. Phase II technical reports and other selected documents are available online at www.hsri.org/nci.

Twelve states (AZ, CT, KY, MA, MN, NE, NC, PA, RI, VA, VT, WA) participated in Phase II. Four additional states joined during the following year (DE, IA, MT, UT), and seven states joined in 2001 (AL, HI, IL, IN, OK, WV, WY). Virginia, Minnesota, Montana, Illinois and Utah are currently on hiatus. South Dakota, South Carolina, and Maine signed on in 2002. In addition to these states, the local DD authority in Orange County, CA participates as its own entity. State participation in NCI is entirely voluntary.

The Indicators

The survey instrument is designed specifically to measure certain core indicators. Most indicators correspond to single survey items. A few indicators are referenced to clusters of related items. Table 1 presents a crosswalk between core indicators collected using the Consumer Survey Version 2004-2005 and their corresponding survey item(s).

Table 1. Crosswalk of Core Indicators and Survey Questions: Consumer Survey Version 2004 – 2005

<p>Key to codes:</p> <p>BI = background information question</p> <p>Q = consumer interview question (bold indicates question allows consumer responses only)</p> <p>S = Day/Vocational/Educational Supplement</p> <p><i>Italics indicate a revised or new indicator in 2004-2005.</i></p>	
Question:	Refers to Core Indicator:
BI-16	The proportion of people taking medications for mood disorders, anxiety, behavior problems, <i>or psychotic disorders.</i>
BI-19	The proportion of people who have had a physical exam in the past year.
BI-20	The proportion of women who have had a GYN exam in the past year.
BI-21	The proportion of people who have had a routine dental exam in the past six months.
BI-22-24	<i>The proportion of people who maintain healthy habits in such areas as smoking, weight, and exercise.</i>
BI-31	The proportion of people who are exercising self self-determination with regard to the services they receive.
Q1	The proportion of people who are satisfied with their job or day program.
Q2, Q7	The proportion of people indicating that most support staff treat them with respect.
Q3	The proportion of people satisfied with where they live.
Q4	The proportion of people who report satisfaction with the amount of privacy they have.
Q5, Q6	The proportion of people who report that they feel safe in their home and neighborhood.

Q8, Q9, Q46-Q48	The proportion of people whose basic rights are respected by others.
Q11	The proportion of people who have friends and caring relationships with people other than support staff and family members.
Q10	The proportion of people who have a close friend, someone they can talk to about personal things.
Q12, Q14	The proportion of people who are able to see their families and friends when they want.
Q13	The proportion of people who feel lonely.
Q15	The proportion of people who know their service coordinators.
Q17	The proportion of people reporting that service coordinators help them get what they need.
Q16	The proportion of people who report that their service coordinators asked about their preferences.
Q18	The proportion of people who have an advocate or someone who speaks on their behalf.
Q19, Q20	The proportion of people reporting that they received support to learn or do something new in the past year.
Q21	<i>The proportion of people who are satisfied with their personal lives.</i>
Q22	The proportion of people who report having adequate transportation when they want to go somewhere.
Q23, Q24	<i>The proportion of people who control their own budgets.</i>
Q28-Q34	The proportion of people who participate in everyday activities in their communities.
Q35, Q37- Q41, Q43, Q45	The proportion of people who make choices about their everyday lives.
Q44	The proportion of people reporting that they choose what to buy with their own spending money.
Q36, Q42	The proportion of people who report having been provided options about where to live and work.
Q49	The proportion of people who have participated in activities of self-advocacy groups or other groups that address rights.
Q50	The rate at which people report that "needed" services were not available.

S1-S6	The average monthly earnings of people who have jobs in the community.
S1-S6	The average number of hours worked per month for people with jobs in the community.
S1-S6	The percent of people earning at or above the state minimum wage.
S9	Of people who have a job in the community, the percent who were continuously employed during the previous year.
S10	Of people who have a job in the community, the percent who receive job benefits.
S11	Of people who have a job in the community, the average length of time people have been working at their current job.

III. Consumer Survey

The National Core Indicators Consumer Survey was initially developed by a technical advisory subcommittee with the purpose of collecting information directly from individuals with developmental disabilities and their families or advocates. The survey is designed to measure over half of the original 60 core indicators. Many questions were drawn from survey instruments already in use in the field; other questions were developed specifically for NCI. NCI staff have tested and refined the instrument each year based on feedback from interviewers.

Organization of the Survey

The Consumer Survey is composed of a pre-survey form and three sections.

- THE PRE-SURVEY FORM collects information necessary to schedule face-to-face interviews, including contact information for consumers, and the names of guardians, advocates, or other individuals who might be asked to provide responses. The form also was used by surveyors to identify special communication needs that individuals might have prior to conducting the interview, define terms the individual would be most familiar with (such as “case manager” or acronyms), and document that informed consent was obtained. In most instances, information for the pre-survey form was obtained from the individual’s case manager. [Note: Individual identifying information was excluded from data submitted to HSRI.]
- THE BACKGROUND INFORMATION SECTION requests data that would most likely be found in agency records or information systems. In some states, case managers complete this section at the same time the pre-survey form is completed. In other states, surveyors complete the section during the direct interview.
- SECTION I of the survey, which concerns questions aimed at obtaining expressions of satisfaction and opinions from each individual, may be completed only through a direct interview with the individual; proxy responses are not acceptable.

- SECTION II questions are to be answered by the individual if possible. If the person is unable to respond to Section II, another person who knows the individual well (e.g., family, friend, support worker) is asked to provide answers to these questions.
- The last page of the survey is the SURVEYOR FEEDBACK SHEET. Surveyors are asked to record the length of the interview with the individual and describe any problematic questions.
- The DAY/VOCATIONAL/EDUCATIONAL SUPPLEMENT is an optional add-on to the survey instrument. These data are generally collected at the same time the background information section is completed.

Note on Self-Determination Questions

The current survey includes items related to self-determination in the background section (BI-31 through BI-36) and two new questions about knowledge of individual budgets in Section I of the direct interview (Q23-Q24). These indicators are not included in this report due to inconsistencies in data collection. During the next year, these questions will be evaluated and considered for revision. Additional questions related to self-determination were developed and tested in one participating state in 2005-2006. These items will also be considered in the next survey revision.

IV. Methods

Criteria for Exclusion of Responses

All persons selected in the survey sample are given an opportunity to respond to questions in a face-to-face interview. There is no pre-screening procedure. Exclusion of responses is done at the time of data analysis, based on specific criteria described below.

The total number of surveys administered in **Phase VII** was **7925**. Section I is administered only to **the person receiving services**. A person's responses are excluded if any of the following criteria are met:

- ◆ The consumer responded to less than half of the questions in Section I.
- ◆ The interviewer recorded that the person did not understand the questions being asked
- ◆ The interviewer recorded that the person gave inconsistent responses.

After excluding incomplete and inconsistent responses, the number of valid respondents to Section I = 5,294. Overall, **67% (5,294/7,925)** of consumers in the total sample were able to respond to Section I of the direct interview. The **“%Valid Answers To Section I”** column in Table 2 indicates the percentage of consumers who were able to respond to Section I, by state.

Section II allows multiple respondents. The **“% Consumer Respondents Section II”** column in Table 2 indicates that a consumer was **one of the respondents** to Section II. Other informants (e.g., family, friend, support worker) may have provided answers to some of the questions. In the final analysis, if a respondent is excluded from Section I, his or her responses are also excluded from Section II. Otherwise, **all responses to questions in Section II are included in the analysis**, regardless of how many questions were answered. Thus, the consumer response rate to Section I may be lower than the response rate to Section II due to stricter criteria for including Section I responses. The number of responses to Section II = 7,322. Overall, **67.5% (4,944/7,322)** of responses to Section II included consumer responses.

Sampling

The goal of each state was to conduct a minimum of 400 interviews. Each state drew a random sample of individuals over age 18 who were receiving at least one service, besides case management. Most states also drew an over-sample to account for refusals. Some states did not complete 400 interviews, and others exceeded this goal. Those that did not complete 400 are included in this report; however, readers are cautioned to take sample sizes into consideration when comparing results across states. Table 2 presents the number of surveys completed and response rates to each section, by state.

Table 2. Valid Number of Surveys and Response Rates, By State

<i>State</i>	<i>Valid Answers To Section 1</i>	<i>Consumer Respondent To Section 2</i>	<i>Final Sample Size</i>	<i>% of Total Sample Size</i>
AL	54.1	57.7	401	5.1
CT	63.6	96.1	428	5.4
DE	59.4	51.3	224	2.8
HI	56.2	55.7	406	5.1
IN	80.7	81.3	810	10.2
KY	62.9	92.8	509	6.4
ME³	70.7	N/A	297	3.7
NC	61.3	73.1	489	6.2
OK	50.2	39.6	414	5.2
PA	75.1	72.9	1349	17.0
RCOC	75.0	73.5	619	7.8
RI	76.3	76.8	384	4.8
SC	69.2	70.5	530	6.7
VT⁴	50.4	50.4	373	4.7
WV	54.3	50.5	289	3.6
WY	67.0	67.3	403	5.1
Total	66.8	67.1	7925	100.0

Administration

All participating states used the survey tool developed by the project, with the exception of Vermont and Pennsylvania, which have integrated the NCI questions into their own statewide survey tools. States used a variety of types of surveyors, including: consumers and families, university students, and state personnel. Some independent interviewers were paid; others were unpaid volunteers. All of the above methods were acceptable and no major differences were noted in terms of using different types of interviewers. The only stipulation was that if case managers are used, they do not interview consumers on their own caseload⁵.

³ Maine's interview schedule is based on a rolling sample administered during the calendar year; the surveys included here represent a portion of the total sample.

⁴ The State of Vermont used a survey tool called the *Self-Perceived Satisfaction Scale*, developed by Susan Culbert, Ph.D. and Sara Burchard, Ph.D. of the University of Vermont. The survey has been in use for several years and has been adapted to align with the NCI Consumer Survey. Vermont only allows the interview to be completed by individuals receiving supports. Surrogate responses are not accepted. For those individuals who do not complete the survey for whatever reason, demographic information only is collected. Vermont's sample included a total of 373 individuals, 188 who responded to the survey and 185 for whom demographic information only was collected. The response rate of 50.4 reported here is calculated by dividing the number of survey respondents (188) by the total number of individuals in the sample (373).

⁵ The State of Maine is transitioning from a previously established Quality of Life survey process to the NCI survey process. The interviewers are assigned differently and may include individuals' case managers or provider staff.

Training

“Train-the-trainer” sessions were provided to the lead agencies from each state. These trainings were conducted by conference call. The first part of the training reviewed the survey tool in detail, question by question. The second part reviewed general interviewing techniques. The participants, or “trainers” from each state, then conducted training with the actual interviewers. NCI provided a packet of standardized materials (including scripts for contacting respondents, frequently asked questions, general interviewing tips and skill exercises) to be used at these in-state training sessions.

V. Data Analysis

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data files received are reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. An outcome adjustment procedure is performed on selected outcomes. See Appendix A for specific rules used to recode, collapse, and adjust outcome variables.

Outcome Adjustment

Outcome adjustment or “risk adjustment” is a statistical process used to control for differences in the individual characteristics of people interviewed across states. This method effectively “levels the playing field” across states. It is necessary to perform this analysis because a state that has a broad eligibility definition (i.e., serves people with autism, brain injury, or other developmental disability) will probably have a sample that looks slightly different from a state that only serves people diagnosed with MR. Other reasons, such as sampling biases, may also affect the nature of the sample.

Only those indicators that are likely to be affected by individual characteristics are adjusted; the rest are not adjusted. For example, a person who has limited mobility and frequent seizures might be less likely to participate in shopping or other community activities. On the other hand, such characteristics should not affect whether a person has friends or has contact with his or her service coordinator. Items are “adjusted” using a logistic regression model. Earlier in NCI, a detailed analysis involving ICAP⁶ data determined a number of individual characteristics that were found to predict outcomes on the Consumer Survey. These individual characteristics are used as regression variables and include: age, gender, legal status, level of MR label, other diagnoses, primary means of expression, and vision⁷.

The predicted values created by the logistic regression represent the “adjusted mean proportion” for each state. Essentially, the predicted value represents what one would expect the outcome to be if all factors were equal across samples. For outcomes that are adjusted, the column heading in the data table will read “Adjusted Mean Proportion.” Keep in mind that these figures are in fact estimates, so they will differ from what is

⁶ The Inventory for Client and Agency Planning is a tool that measures a variety of functional and behavioral characteristics. A full report of this analysis is available online at: http://www.hsri.org/docs/786_P1_Outcome_Adjustment.rtf.

⁷ The following items were not included in the outcome adjustment procedure this year due to missing data in a number of states: mobility, frequency of seizures, frequency of medical care required, and the presence of problem behavior.

displayed in the item-by-item tables presented in Appendix C. Also note that the Valid N column represents the number of cases used in the regression analysis. Only cases that have valid answers for ALL adjustment factors are included in the regression analysis; therefore, the Valid N may be reduced due to missing data. The types of outcomes that are subject to adjustment include: Community Inclusion, Choice and Decision-making, some Access items, and some Rights items. Appendix A, Table 85-86 indicates the specific variables that are adjusted.

Scale Development

For the sub-domains of Community Inclusion and Choice and Decision-making, we were able to combine certain items into reliable scales. There are a total of three scales. The Community Inclusion scale and the two Choice scales were created using adjusted figures. The scale scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. Each scale is described in further detail in the results section of this report.

A scale can be considered a reliable measure if its internal consistency is ≥ 0.70 . The statistic that assesses the scale's reliability is called Cronbach's alpha. In other words, if the alpha is ≥ 0.70 , we can be fairly confident that items are measuring the same dimension. Alpha scores are also included in the results sections.

Significance Testing

All four scales were tested for significant differences across states, and between each state and the national average. Each state's scale score was compared with the average scale score across all other states (not including that state). A conservative cutoff point ($p \leq 0.01$) was used to determine significant differences. These results are displayed below in table and map formats.

Analysis of variance is a collection of techniques used to test for differences among more than two groups. Post hoc (multiple comparison) tests provide information about which groups are different from each other. One such analysis, called Tukey's test, was performed to determine "homogeneous subsets" of results, i.e., groups of states that are not significantly different from one another. Subsets are arranged by column and labeled with a number at the top of each column. Scores that fall in the same subsets are not significantly different.

VI. Results: Demographic Characteristics of Respondents

First, we present descriptive information about the sample of respondents. Fifteen states plus the Regional Center of Orange County administered the consumer survey in 2004-2005 and together conducted a total of 7925 interviews. The participating states represented are: AL, CA – Regional Center Orange County (RCOC), CT, DE, HI, IN, KY, ME, NC, OK, PA, RI, SC, VT, WV and WY. Respondent characteristics are summarized in the following tables.

Table 3. Gender

<i>State</i>	<i>Male</i>	<i>Female</i>	<i>N</i>
AL	57.0	43.0	398
CT	50.5	49.5	418
DE	59.4	40.6	224
HI	50.7	49.3	406
IN	55.7	44.3	810
KY	54.8	45.2	509
NC	57.3	42.7	461
OK	62.8	37.2	414
PA	54.4	45.6	1340
RCOC	56.2	43.8	619
RI	55.2	44.8	384
SC	57.2	42.8	530
VT	60.9	39.1	373
WV	54.0	46.0	287
WY	52.6	47.4	403
Total	55.7	44.3	7576

Table 4. Race

State	American Indian or Alaska native	Asian	Black or African American	Pacific islander	White	Other race not listed	Two or more races	N
AL	0.5	0.0	29.0	0.0	69.7	0.3	0.5	390
CT	0.5	0.2	10.9	0.5	80.4	4.2	3.2	404
DE	0.5	0.5	30.8	0.0	67.0	0.9	0.5	221
HI	0.2	55.9	1.0	4.0	16.1	4.5	18.3	404
IN	0.4	0.2	7.5	0.4	90.9	0.5	0.1	810
KY	1.0	0.4	9.7	0.0	88.7	0.2	0.0	506
NC	1.5	0.4	41.4	0.0	55.3	1.3	0.0	461
OK	5.1	0.2	12.4	0.0	80.8	1.5	0.0	411
PA	0.2	0.3	4.3	0.2	93.5	1.3	0.2	1338
RCOC	0.3	10.6	2.1	0.0	62.7	22.9	1.5	616
RI	0.3	0.3	3.7	0.0	91.6	3.4	0.8	381
SC	0.2	0.2	47.0	0.0	52.1	0.6	0.0	530
VT	1.2	0.3	0.3	0.0	97.9	0.3	0.0	340
WV	0.7	1.0	3.1	0.0	94.8	0.3	0.0	289
WY	2.2	0.2	0.7	0.2	96.3	0.2	0.0	403
Total	0.9	4.1	12.4	0.3	77.8	3.1	1.4	7504

Table 5. Ethnicity

State	Non-Hispanic	Hispanic	Don't Know	N
AL	98.2	1.8	0.5	395
CT	94.6	5.4	1.9	404
DE	99.1	0.9	3.1	217
HI	98.0	2.0	1.0	402
IN	98.8	1.2	0.5	806
KY	98.2	1.8	0.2	494
NC	99.1	0.9	0.9	446
OK	98.3	1.7	0.0	414
PA	97.9	2.1	2.2	1306
RCOC	77.3	22.7	1.0	613
RI	97.1	2.9	1.8	377
SC	99.4	0.6	0.0	501
VT	100.0	0.0	9.1	339
WV	97.6	2.4	1.0	286
WY	99.3	0.7	0.0	403
Total	96.5	3.5	1.5	7513

Table 6. Level of MR

State	No MR label	Mild	Moderate	Severe	Profound	N
AL	0.3	24.3	25.8	15.7	33.9	395
CT	1.5	38.6	29.2	18.9	11.8	407
DE	0.5	25.7	30.4	29.4	14.0	214
HI	1.8	20.9	34.8	20.1	22.4	388
IN	2.2	50.0	25.1	12.3	10.5	790
KY	3.1	31.2	30.6	19.0	16.1	484
NC	5.5	36.7	25.4	13.4	18.9	417
OK	0.0	39.7	17.9	17.3	25.1	375
PA	0.8	48.2	26.3	14.9	9.8	1316
RCOC	9.2	43.7	25.7	12.8	8.6	618
RI	3.8	43.0	32.2	12.9	8.2	342
SC	3.7	31.8	32.3	20.1	12.0	507
VT	2.2	58.0	26.0	10.8	3.0	369
WV	3.3	26.7	34.4	25.6	10.0	270
WY	4.9	58.7	21.3	8.2	6.9	390
Total	2.8	40.7	27.3	15.8	13.3	7282

Table 7. Other Disabilities (Duplicated Counts)

State	Mental illness/psychiatric diagnosis	Autism	Cerebral palsy	Brain injury	Seizure disorder/neurological problem	Chemical dependency	Vision and/or hearing impairments	Physical disability	Communication disorder	Alzheimer's disease	Down syndrome	Other disability
AL	30.2	3.9	12.3	1.0	35.7	0.3	8.8	4.6	13.5	0.7	9.0	12.4
CT	37.4	8.6	11.4	2.6	25.2	1.6	28.0	15.2	12.6	2.1	10.5	21.5
DE	18.8	14.3	9.4	1.8	22.9	0.9	21.1	20.2	16.1	2.2	7.6	26.5
HI	7.4	4.7	7.6	1.0	30.5	0.0	10.8	9.1	2.5	0.0	10.1	39.9
IN	21.6	7.4	14.1	2.5	25.2	1.2	18.9	16.4	18.5	0.7	10.0	31.7
KY	39.7	4.7	18.7	3.5	25.9	0.8	16.1	17.3	9.2	1.0	6.3	33.0
NC	38.6	10.4	8.5	6.1	21.9	1.7	15.8	11.3	11.5	0.7	4.3	25.6
OK	29.5	4.3	17.4	1.9	35.5	0.2	51.0	31.0	21.5	1.0	6.0	65.7
PA	39.2	5.0	12.1	3.0	26.4	0.6	21.2	15.2	9.7	1.3	9.9	19.4
RCOC	31.7	8.6	26.8	2.3	27.1	0.5	16.8	6.9	2.6	0.0	9.4	17.6
RI	23.2	4.7	12.0	2.9	27.9	0.5	22.4	13.3	13.5	1.3	10.4	23.7
SC	20.2	6.1	11.3	1.0	20.0	0.8	17.0	11.8	10.7	0.6	8.4	23.5
VT	23.9	6.2	9.7	3.2	21.2	1.3	27.3	12.6	9.1	1.1	8.8	16.1
WV	29.8	19.4	28.0	14.9	38.1	6.2	40.5	36.0	41.9	4.8	15.9	30.8
WY	33.3	3.0	10.9	0.0	33.7	2.2	3.5	35.0	.0	0.0	12.7	17.4
Total N	7336	7326	7327	7319	7321	7320	7324	7317	7324	7325	7328	7330
Total	29.5	6.9	14.1	3.0	27.2	1.1	20.7	16.2	11.9	1.0	9.2	26.4

Table 8. Type of Residence

State	Specialized facility	Group home	Apartment program	Independent home/apt	Parent/relative's home	Foster care/host home	Nursing facility	Other	N
AL	13.5	45.1	13.8	1.8	24.6	0.3	0.8	0.3	399
CT	7.2	44.8	6.0	14.5	22.2	3.6	0.5	1.2	415
DE	17.0	23.2	9.4	3.1	26.8	17.9	0.0	2.7	224
HI	0.0	5.2	1.5	2.2	43.3	45.8	0.5	1.5	406
IN	6.0	16.3	3.3	29.9	36.8	3.3	3.7	0.6	810
KY	17.8	19.2	14.4	6.2	24.4	10.8	0.6	6.8	501
ME	10.7	41.6	16.5	14.1	9.6	1.0	0.0	6.5	291
NC	15.5	22.8	3.1	12.3	33.7	5.0	0.7	7.0	457
OK	15.7	20.0	0.2	52.4	1.4	7.7	0.0	2.4	414
PA	6.7	27.1	2.7	12.4	35.6	4.6	2.5	8.4	1334
RCOC	11.0	30.7	1.5	15.4	39.0	0.8	0.3	1.3	618
RI	0.8	37.6	5.5	18.0	37.1	0.0	0.3	0.8	383
SC	9.0	19.6	7.5	10.4	46.0	1.2	0.2	6.2	520
VT	0.0	6.7	1.1	24.9	28.7	37.0	0.5	1.1	373
WV	0.7	6.8	2.9	18.0	62.9	7.6	0.4	0.7	278
WY	2.7	55.1	7.4	16.9	16.6	0.7	0.0	0.5	403
Total	8.3	26.1	5.3	16.2	31.7	7.9	1.1	3.6	7826

Table 9. Age

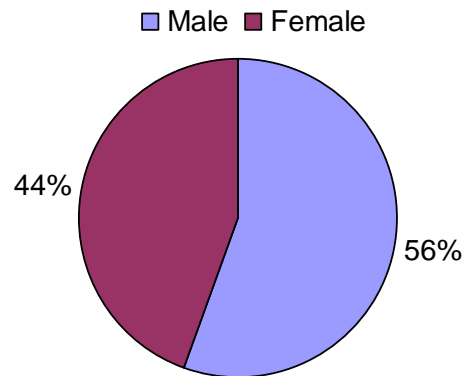
State	N	Minimum	Maximum	Mean
AL	390	18	82	43.9
CT	402	19	100	43.8
DE	224	20	89	42.9
HI	406	18	86	42.2
IN	744	18	98	43.3
KY	496	22	69	43.4
NC	451	18	81	39.7
OK	407	19	77	40.1
PA	1315	18	91	43.6
RCOC	619	18	86	37.5
RI	384	21	86	43.6
SC	515	18	68	39.2
VT	370	19	89	42.0
WV	289	18	77	37.0
WY	403	21	84	41.4
Total	7415	18	100	41.8

Demographic Profile of Sample

This section summarizes selected demographic characteristics of the overall sample.

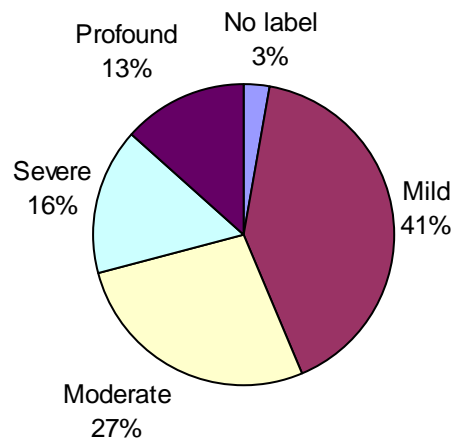
- » Most states had a slightly higher percentage of males in their samples. Overall, the total sample was 56% male and 44% female.

Figure 1. Gender (N= 7576)



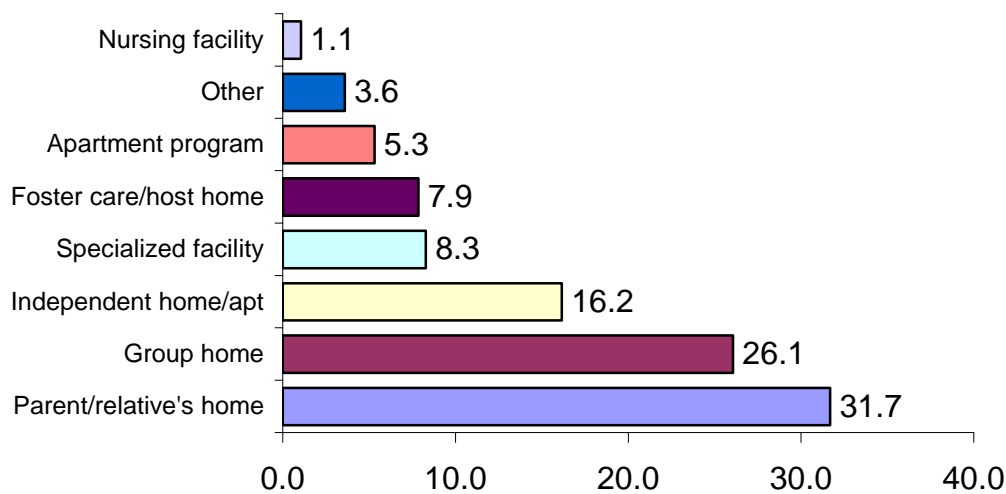
- » The average age of respondents was 42 years old, with a range of ages from 18 to 100.
- » The reported levels of mental retardation among respondents varied by state. Overall, about 68% of the sample had a diagnosis of “mild” or “moderate” MR, and 29% had a diagnosis of “severe” or “profound” MR.

Figure 2. Level of MR (N=7282)



- » 20% of respondents in the total sample used a nonverbal form of communication as their primary means of expression (e.g., gestures, sign language, communication device).
- » The overall sample of respondents included the following racial and ethnic diversity: 12.4% identified their race as Black or African American; 4.4% reported their race as Asian, Native Hawaiian, or Other Pacific Islander; and .9% reported their race as American Indian or Alaska Native. Another 4.5% reported their race as “Other” or “Mixed Race.” In addition, 3.5% reported their ethnicity as Hispanic.
- » Overall, 32% of the total respondents live with their families, although this figure varies by state. The percent of respondents living in other types of homes is shown in the table below.

Figure 3. Type of Residence (N= 7826)



- » Overall, 29.5% of the total respondents also were reported to have a mental illness/psychiatric diagnosis, and 27.2% had a diagnosis of seizure disorder or other neurological problem.
- » The types of day/employment services and supports received by respondents varied by state. Overall, about 23% receive supported employment services, 16% receive group employment services, 36% receive facility-based vocational services, and 42% receive non-vocational day services.
- » 61% of respondents in the overall sample receive Home and Community Based Waiver Services; 18% receive ICF/MR funding.

Additional Outcome Adjustment Variables

Several variables related to individual characteristics are used to “adjust” certain consumer outcome results. The adjustment variables include demographic information such as age, gender, level of MR, and other disabilities diagnosed. Additional adjustment factors are displayed in the following tables, by state and for the sample as a whole.

Table 10. Consumer Legal Status

State	Independent of guardianship	Private guardian or conservator	Public guardian or conservator	DK	N
AL	52.0	46.7	0.5	0.8	394
CT	25.9	71.1	2.4	0.5	409
DE	62.1	27.2	7.6	3.1	224
HI	30.0	42.9	27.1	0.0	406
IN	66.9	31.5	0.2	1.4	810
KY	34.7	45.4	19.7	0.2	498
NC	47.5	43.3	7.0	2.2	457
OK	41.3	55.1	2.2	1.4	414
PA	82.3	12.1	0.7	4.9	1334
RCOC	88.5	10.3	1.0	0.2	619
RI	77.1	19.0	1.6	2.3	384
SC	75.2	13.8	1.7	9.3	529
VT	33.2	44.8	21.7	0.3	373
WV	30.4	64.4	4.2	1.0	289
WY	33.0	67.0	0.0	0.0	403
Total	57.8	34.6	5.4	2.2	7543

Table 11. Language

State	English	Other	N
AL	99.0	1.0	396
CT	97.5	2.5	405
DE	99.1	0.9	224
HI	98.5	1.5	266
IN	99.1	0.9	692
KY	99.2	0.8	505
NC	97.4	2.6	459
OK	98.8	1.2	414
PA	98.8	1.2	1344
RCOC	78.7	21.3	619
RI	98.4	1.6	384
SC	94.5	5.5	523
VT	99.5	0.5	372
WV	98.6	1.4	288
WY	99.8	0.2	403
Total	96.8	3.2	7294

Table 12. Primary Means of Expression

State	Speaks English	Uses gestures	Uses sign language	Uses communication device	Other	DK	N
AL	68.3	28.4	0.3	0.3	2.5	0.3	398
CT	74.3	21.6	1.7	1.0	1.0	0.5	416
DE	65.6	29.9	0.9	0.9	1.3	1.3	224
HI	65.5	18.7	2.0	0.2	13.5	0.0	406
IN	85.5	7.3	1.1	1.9	4.0	0.2	809
KY	66.6	27.5	2.6	1.0	2.4	0.0	506
NC	76.4	19.9	1.1	1.3	1.3	0.0	457
OK	70.0	14.0	0.5	0.7	14.7	0.0	414
PA	79.9	17.2	1.1	0.4	0.7	0.6	1345
RCOC	82.7	11.6	1.8	1.1	1.1	1.6	619
RI	77.3	14.8	4.9	0.5	1.6	0.8	384
SC	80.5	16.8	1.1	0.0	0.0	1.6	185
VT	80.2	15.3	1.6	0.5	1.6	0.8	373
WV	66.1	25.3	3.5	1.7	2.4	1.0	289
WY	84.1	4.0	2.5	1.5	1.2	6.7	403
Total	76.4	17.0	1.7	0.9	3.1	0.9	7228

VII. Results: Core Indicator Outcomes and Comparisons across States

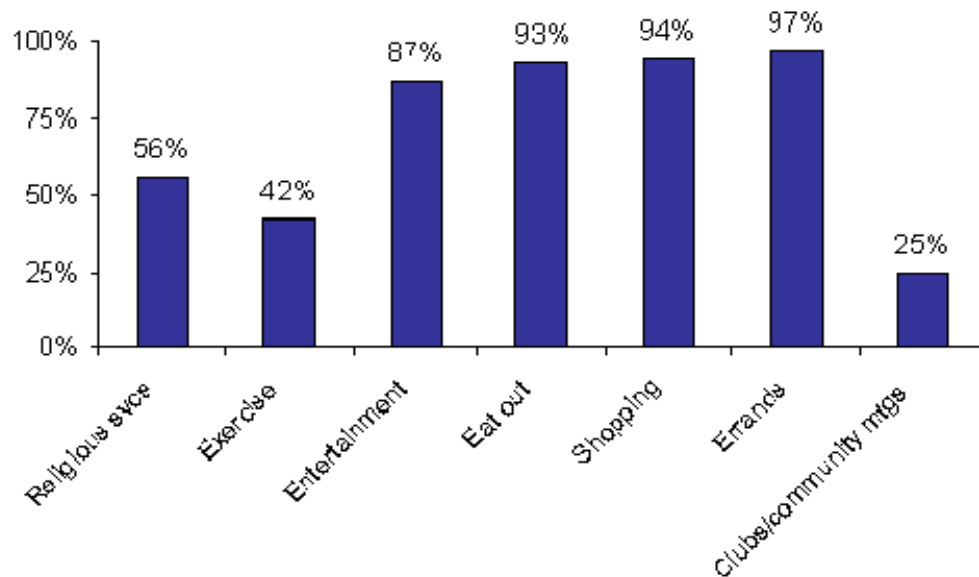
The data from the Consumer Survey were analyzed to assess core indicator outcomes for the sample as a whole and separately by state. The following brief summary highlights national results from FY2005 NCI data.

Summary of Aggregate Results

Community Inclusion

- » For most types of community activities asked about in the survey, participation was high, ranging from 73% to 97%. Two activities had lower participation: 56% attended religious services, and 25% reported belonging to clubs or community organizations.

Figure 4. Community Inclusion – Adjusted Results for Total Sample



Respect and Rights

- » 93% of all respondents report that they can be alone if they want to.
- » 25% of all respondents reported having attended a self-advocacy group meeting or event.
- » Across the board, most respondents report that residential support staff (89%) and day support staff (93%) treat them with respect.

Service Coordination

- » 81% of respondents report that they know their service coordinators.
- » 84% of all respondents report that service coordinators get them what they need.
- » 81% report that service coordinators ask them what is important.

Access

- » 82% of respondents reported that needed services were available.

Satisfaction

- » Satisfaction with home was 88% and satisfaction with work/day program was 91%.

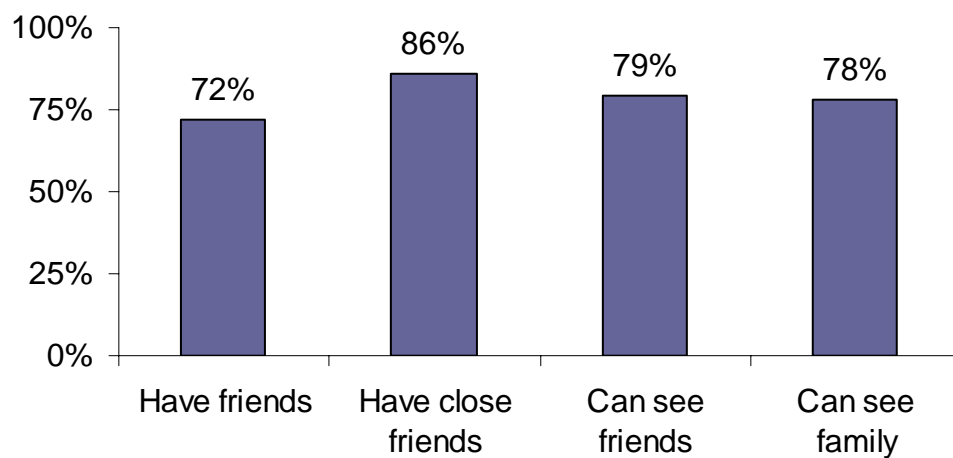
Choice

- » 56% of respondents reported that they had input in choosing where they live.
- » 63% of respondents reported having input in choice of staff who work with them at home; 65% reported having input in choice of staff who help them at work or day program.

Relationships

- » The majority of respondents report having friends other than family and staff (70%), best friends (85%), and being able to see their friends (82%) and family (80%) when they want to.
- » More than half of the respondents (57%) reported “sometimes” or “often” feeling lonely.

Figure 5. Relationships – Results for Total Sample



Safety

- » 84% of respondents reported feeling safe in their homes, and 83% reported feeling safe in their neighborhood.

Health & Well-Being

- » 46% of respondents take at least one kind of psychotropic medication (for mood, anxiety, behavior or psychotic issues).
- » Across the board, women's access to yearly GYN exams continues to be low (only 56% had an exam in the past year and 7% have never had one).
- » 27% of respondents are overweight and 22% report being inactive.
- » 80% of respondents report that they do not smoke or use chewing tobacco.

Figure 6. Time of Last Physical Exam (N= 7850)

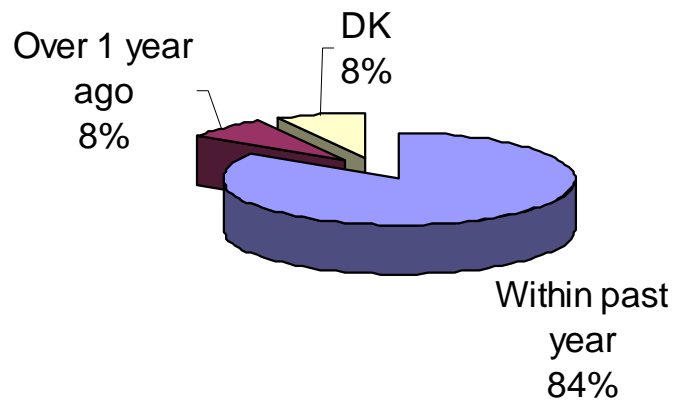


Figure 7. Time of Last Dental Exam (N= 7816)

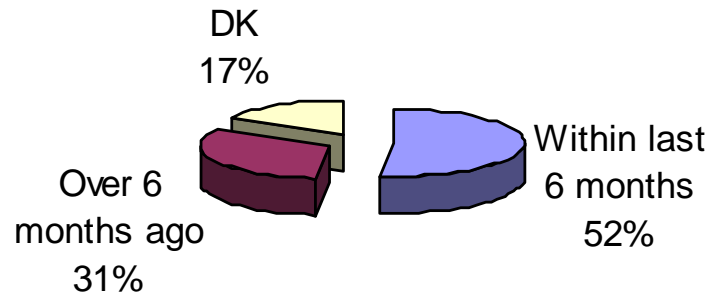


Figure 8. Time of Last GYN Visit (N=3270)

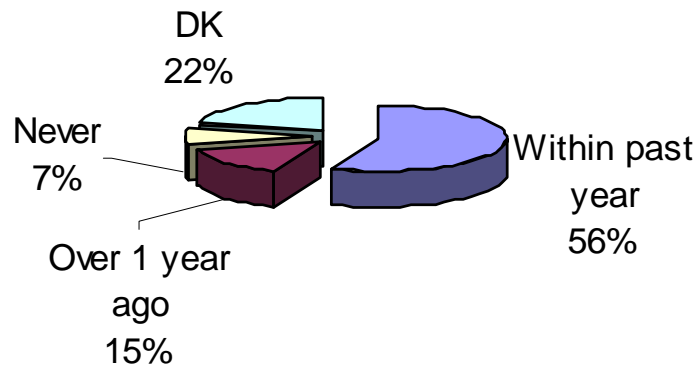


Figure 9. Weight Issues (n= 5987)

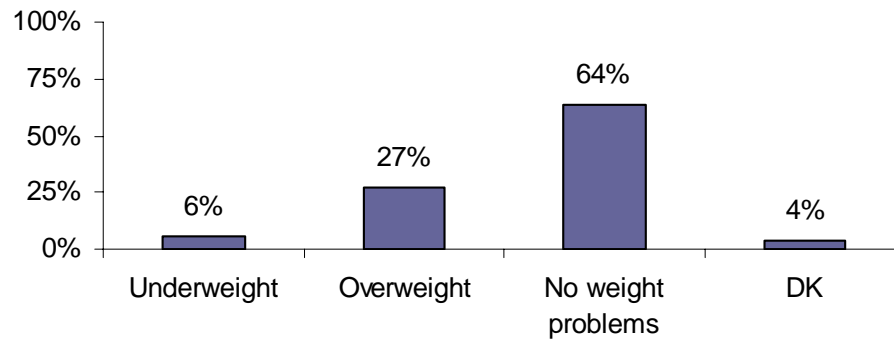


Figure 10. Exercise (n= 5987)

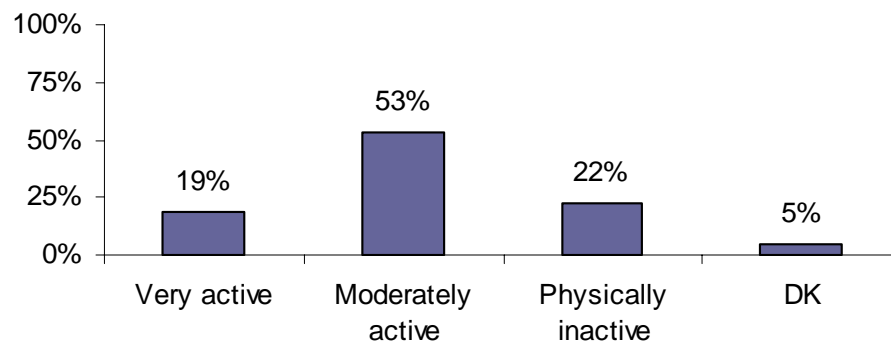
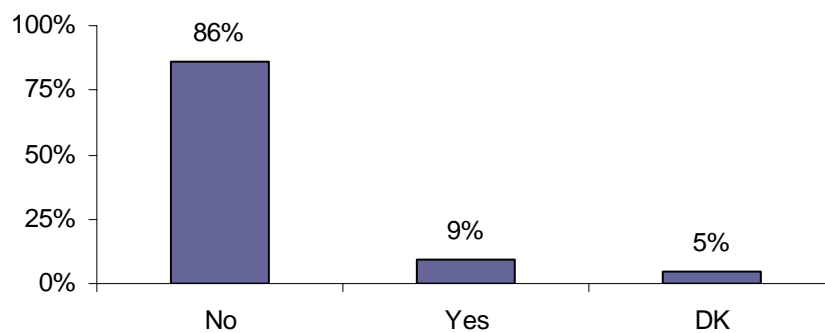


Figure 11. Smoke or Chew Tobacco (n= 5989)



Presentation of Detailed Results by State

The results are organized according to the current list of Core Indicators. Each section represents one Sub-domain and contains the following information:

- Concern statement for the Sub-domain
- Indicators in that Sub-domain measured by the Consumer Survey
- Statistics provided for **all** indicators:
 - ♦ **Mean proportion** (either adjusted or non-adjusted) for each state and for the total sample
 - ♦ Two “summary” measures are displayed. (1) The “TOTAL” row is simply the aggregate of all responses across all states. This measure does not take into account the different state sample sizes. (2) The “STATE AVERAGE” row represents the mean across all states. Thus, all states are equally represented in this measure, regardless of sample size.
 - ♦ **Valid N** for each state and for the total sample
- Additional statistics provided **only for scale scores** -- Community Inclusion, Life Decisions (previously called “Supports-Related Choices”), and Everyday Choices (previously called “Personal Choices”):
 - ♦ Significance testing for **each state vs. the national average**
 - ♦ Significant differences **among states** (Tukey’s test)
- The results for the states are indicated by the two letter abbreviations.
- Tables that display “adjusted” results are so noted. For these indicators, the sample sizes may be slightly smaller because cases that are missing data for the adjustment variables drop out of the analysis.
- Question-by-question, “raw” results are included in Appendix C of this report. States may find the raw results useful for probing further into the breakdown of responses to specific questions.
- Broadly, the “STATE AVERAGE” figures constitute benchmarks for comparing states. For example, when a particular state’s mean score is appreciably higher than the cross-state average, the quality or characteristic is better reflected in the state’s system than in others.
- On the other hand, in states where the mean score is appreciably lower than the cross-state average, then there is a valid basis for stakeholders to probe further.

- In no instance should the cross-state averages be interpreted as necessarily defining “acceptable” levels of performance or satisfaction. Instead, they are a multi-state “norms” that describe present levels of performance or satisfaction across the participating states. Where no significant differences were found state-to-state, it means that all states are performing about the same. Where significant differences were found and scores are especially high (considerably above the average level) in one or two states, the levels of satisfaction achieved there might define a level of performance that may serve as a guidepost for other states.
- Data from previous years are not presented in this report. **Comparisons of results from year to year should be made with caution**, for three reasons: (1) even slight changes in wording or response options of certain questions may affect comparability of results from one year to the next; (2) the mix of participating states differs slightly each year and may affect the “total sample” results; and (3) the states draw new samples each year rather than following the same group of individuals. **Appendix D includes a crosswalk of consumer survey questions from year to year, and indicates item comparability across years.**

Consumer Outcomes: Work

The Work Sub-domain has the following concern statement: “People have support to find and maintain community integrated employment.” There are six work indicators measured using the supplement to the Consumer Survey:

1. The average monthly earnings of people who have jobs in the community.
2. The average number of hours worked per month for people with jobs in the community.
3. The percent of people earning at or above the state minimum wage.⁸
4. Of people who have a job in the community, the percent who were continuously employed during the previous year.
5. Of people who have a job in the community, the percent who receive job benefits.
6. Of people who have a job in the community, the average length of time people have been working at their current job.

IMPORTANT NOTE ABOUT THE DATA SOURCE

A review of previous data collection efforts concluded that the most preferable way to collect the employment data was through the Consumer Survey supplement, *unless* a state already had a good system in place for obtaining the information from providers (e.g., Vermont and Washington). Massachusetts decided to create a new reporting system (adapted from the original Provider Survey protocol) that would require provider agencies by contract to report employment information on an annual basis. One advantage to using the Consumer Survey supplement is the potential ability to link the employment information with other person-level data collected in the survey. The major drawback at this time is that the information is only collected on a sample of the service population (usually about 400 individuals), and once the data is broken down by type of employment, the Ns are very small in some categories.

The current version of the supplement form is entitled “Day/Vocational/Educational Support” and expands on the basic survey by requesting additional information about competitive employment, enrollment in public school, funding streams, job benefits, and length of employment in the community.

In Phase VII, seven states collected data using the Consumer Survey supplement (CT, ME, OK, PA, RCOC, WV, and WY) and two states submitted data from their own systems (VT and WA). Data extracted from state systems are from FY2004. Data collected using the Consumer Survey supplement are from FY2005.

⁸ Not reported for Phase VI.

Table 13. Earnings and Hours Worked Per Month, By State (Source: Consumer Survey Supplement FY2005)

State	Category of employment	Average Monthly wage	MIN	MAX	N	Average Monthly Hours Worked	MIN	MAX	N
CT	S1. Competitive	\$556.73	\$4.00	\$2,400.00	9	75.0	2	160	9
	S2. Individual supported	\$323.91	\$1.28	\$990.99	11	65.0	16	120	15
	S3. Group Supported	\$250.98	\$7.00	\$740.19	29	65.3	5	150	32
	S4. Facility Based Work Program	\$70.59	\$1.00	\$281.72	22	80.3	2	150	28
	S5. Facility Based Non Work Activities					74.9	20	168	15
	S6. Community Based Non Work Activities					72.3	5	150	30
ME	S1. Competitive	\$286.33	\$6.75	\$700.00	22	45.8	10	106	24
	S2. Individual supported	\$158.68	\$10.00	\$594.00	33	32.5	4	88	33
	S3. Group Supported	\$154.25	\$5.00	\$640.00	12	51.5	1	104	12
	S4. Facility Based Work Program	\$73.04	\$0.80	\$1,037.30	39	38.7	2	110	39
	S5. Facility Based Non Work Activities					60.4	7	140	87
	S6. Community Based Non Work Activities					49.4	4	150	95
OK	S1. Competitive	\$415.89	\$45.00	\$1,011.01	10	77.6	9	160	11
	S2. Individual supported	\$331.80	\$40.00	\$822.00	35	75.3	8	160	40
	S3. Group Supported	\$290.70	\$5.64	\$999.00	76	98.0	4	167	82
	S4. Facility Based Work Program	\$118.70	\$0.00	\$551.20	164	96.3	4	158	185
	S5. Facility Based Non Work Activities					85.6	20	160	10
	S6. Community Based Non Work Activities					56.2	8	120	31

Table 14. Earnings and Hours Worked Per Month, By State – Continued (Source: Consumer Survey Supplement FY2005)

State	Category of employment	Average Monthly wage	MIN	MAX	N	Average Monthly Hours Worked	MIN	MAX	N
PA	S1. Competitive	\$410.56	\$1.71	\$1,390.40	77	66.3	4	160	94
	S2. Individual supported	\$246.99	\$2.92	\$2,010.00	39	51.7	3	160	50
	S3. Group Supported	\$140.86	\$4.00	\$878.11	33	53.3	5	171	45
	S4. Facility Based Work Program	\$95.51	\$0.00	\$710.00	227	88.0	2	180	296
	S5. Facility Based Non Work Activities					83.4	1.5	161	258
	S6. Community Based Non Work Activities					46.1	2	180	169
RCOC	S1. Competitive	N/A							
	S2. Individual supported	\$502.41	\$42.52	\$1,278.80	34	71.3	3	172	36
	S3. Group Supported	\$241.39	\$2.20	\$1,986.05	69	51.8	1	160	69
	S4. Facility Based Work Program	\$79.05	\$5.65	\$906.33	112	54.4	5	157	112
	S5. Facility Based Non Work Activities					74.8	4.25	180	161
	S6. Community Based Non Work Activities					78.4	2	144	121
WV	S1. Competitive	\$156.61	\$2.00	\$800.00	17	45.3	6	160	16
	S2. Individual supported	\$125.38	\$2.00	\$500.00	40	37.3	1	120	47
	S3. Group Supported	\$101.38	\$3.00	\$280.00	8	38.5	6	120	13
	S4. Facility Based Work Program	\$103.76	\$0.00	\$600.00	35	63.0	1	160	34
	S5. Facility Based Non Work Activities					77.0	3	140	82
	S6. Community Based Non Work Activities					56.8	2	180	105

Table 15. Earnings and Hours Worked Per Month, By State – Continued (Source: Consumer Survey Supplement FY2005)

State	Category of employment	Average Monthly wage	MIN	MAX	N	Average Monthly Hours Worked	MIN	MAX	N
WY	S1. Competitive	\$410.56	\$1.71	\$1,390.40	77	66.3	4	160	94
	S1. Competitive	\$349.70	\$20.60	\$1,677.00	22	45.1	4	172	30
	S2. Individual supported	\$266.56	\$6.68	\$980.42	19	43.2	1	152	21
	S3. Group Supported	\$126.86	\$2.15	\$442.00	15	42.4	2	120	16
	S4. Facility Based Work Program	\$166.83	\$0.00	\$762.22	114	62.0	0.5	165	98
	S5. Facility Based Non Work Activities					66.9	2	167	92
	S6. Community Based Non Work Activities					32.2	1	160	68

Table 16. Summary of Monthly Earnings, All States (Source: Consumer Survey Supplement FY2005)

	Mean Monthly Earnings for Total Sample	National Average (seven states)
S1. Competitive	\$365.9	\$362.64
S2. Individual supported	\$271.1	\$279.39
S3. Group Supported	\$228.3	\$186.63
S4. Facility Based Work Program	\$108.1	\$101.07

Table 17. Summary of Monthly Hours Worked, All States (Source: Consumer Survey Supplement FY2005)

	Mean Monthly Hours Worked for Total Sample	National Average (seven states)
S1. Competitive	59.5	59.2
S2. Individual supported	53.2	53.7
S3. Group Supported	66.5	57.2
S4. Facility Based Work Program	78.2	69.0
S5. Facility Based Non Work Activities	75.6	74.7
S6. Community Based Non Work Activities	55.0	55.9

Because the median values for combined wages are lower than the mean values, the mean value can be misleading. Percentiles are displayed in the table below in order to show what the income distribution looks like. For example, in RCOC 50% of people make \$66 or less per month (all work activities combined). In Connecticut, 50% of people make \$197 or less per month.

Table 18. Total Monthly Wages, All Work Activities Combined, by State (Source: Consumer Survey Supplement FY2005)

CT	N	Valid	68	ME	N	Valid	101	OK	N	Valid	274	PA	N	Valid	348
	Mean		\$256		Mean		\$161		Mean		\$209		Mean		\$200
	Median		\$197		Median		\$98		Median		\$147		Median		\$100
	Minimum		\$1		Minimum		\$1		Minimum		\$0		Minimum		\$0
	Maximum		\$2,400		Maximum		\$1,037		Maximum		\$1,011		Maximum		\$2,010
	Percentiles	25	\$36		Percentiles	25	\$27		Percentiles	25	\$45		Percentiles	25	\$40
		50	\$197			50	\$98			50	\$147			50	\$100
		75	\$333			75	\$205			75	\$300			75	\$250
RCOC	N	Valid	215	WV	N	Valid	95	WY	N	Valid	155	ALL	N	Valid	1256
	Mean		\$200		Mean		\$128		Mean		\$217		Mean		\$199
	Median		\$66		Median		\$85		Median		\$119		Median		\$103
	Minimum		\$2		Minimum		\$0		Minimum		\$0		Minimum		\$0
	Maximum		\$1,986		Maximum		\$800		Maximum		\$1,677		Maximum		\$2,400
	Percentiles	25	\$32		Percentiles	25	\$20		Percentiles	25	\$33		Percentiles	25	\$36
		50	\$66			50	\$85			50	\$119			50	\$103
		75	\$230			75	\$200			75	\$330			75	\$264

Table 19. Competitive Employment Wages, by State (Source: Consumer Survey Supplement FY2005)

CT	N	Valid	9	ME	N	Valid	22	OK	N	Valid	10	PA	N	Valid	77
	Mean		\$557		Mean		\$286		Mean		\$416		Mean		\$411
	Median		\$394		Median		\$228		Median		\$362		Median		\$300
	Minimum		\$4		Minimum		\$6.75		Minimum		\$45		Minimum		\$2
	Maximum		\$2,400		Maximum		\$700		Maximum		\$1,011		Maximum		\$1,390
	Percentiles	25	\$53		Percentiles	25	\$96		Percentiles	25	\$55		Percentiles	25	\$133
		50	\$394			50	\$228			50	\$362			50	\$300
		75	\$744			75	\$467			75	\$711			75	\$725
WV	N	Valid	17	WY	N	Valid	22								
	Mean		\$157		Mean		\$350								
	Median		\$77		Median		\$261								
	Minimum		\$2.00		Minimum		\$21								
	Maximum		\$800		Maximum		\$1,677								
	Percentiles	25	\$60.00		Percentiles	25	\$81								
		50	\$77			50	\$261								
		75	\$213			75	\$507								

Table 20. Individual Supported Employment Wages, by State (Source: Consumer Survey Supplement FY2005)

CT	N	Valid	11	ME	N	Valid	33	OK	N	Valid	35	PA	N	Valid	39
	Mean		\$324		Mean		\$159		Mean		\$332		Mean		\$247
	Median		\$280		Median		\$98		Median		\$258		Median		\$182
	Minimum		\$1		Minimum		\$10		Minimum		\$40		Minimum		\$3
	Maximum		\$991		Maximum		\$594		Maximum		\$822		Maximum		\$2,010
	Percentiles	25	\$175		Percentiles	25	\$41		Percentiles	25	\$150		Percentiles	25	\$25
		50	\$280			50	\$98			50	\$258			50	\$182
		75	\$437			75	\$223			75	\$500			75	\$300
RCOC	N	Valid	34	WV	N	Valid	40	WY	N	Valid	19				
	Mean		\$502		Mean		\$125		Mean		\$267				
	Median		\$446		Median		\$100		Median		\$200				
	Minimum		\$43		Minimum		\$2		Minimum		\$7				
	Maximum		\$1,279		Maximum		\$500		Maximum		\$980				
	Percentiles	25	\$275		Percentiles	25	\$40		Percentiles	25	\$115				
		50	\$446			50	\$100			50	\$200				
		75	\$712			75	\$175			75	\$357				

Table 21. Group-Based Work Program Wages, by State (Source: Consumer Survey Supplement FY2005)

CT	N	Valid	29	ME	N	Valid	12	OK	N	Valid	76	PA	N	Valid	33
	Mean		\$251		Mean		\$154		Mean		\$291		Mean		\$141
	Median		\$280		Median		\$103		Median		\$249		Median		\$100
	Minimum		\$7		Minimum		\$5.0		Minimum		\$6		Minimum		\$4
	Maximum		\$740		Maximum		\$640		Maximum		\$999		Maximum		\$878
	Percentiles	25	\$107		Percentiles	25	\$46		Percentiles	25	\$80		Percentiles	25	\$44
		50	\$280			50	\$103			50	\$249			50	\$100
		75	\$361			75	\$214			75	\$416			75	\$178
RCOC	N	Valid	69	WV	N	Valid	8	WY	N	Valid	15				
	Mean		\$241		Mean		\$101		Mean		\$127				
	Median		\$99		Median		\$70		Median		\$79				
	Minimum		\$2		Minimum		\$3.00		Minimum		\$2.15				
	Maximum		\$1,986		Maximum		\$280		Maximum		\$442				
	Percentiles	25	\$33		Percentiles	25	\$9		Percentiles	25	\$36				
		50	\$99			50	\$70			50	\$79				
		75	\$303			75	\$233			75	\$188				

Table 22. Total Hours Engaged in work or non-work occupations, by State (Source: Consumer Survey Supplement FY2005)

CT	N	Valid	118	ME	N	Valid	202	OK	N	Valid	328	PA	N	Valid	751
	Mean		77		Mean		69		Mean		99		Mean		88
	Median		80		Median		79		Median		120		Median		100
	Minimum		2		Minimum		2		Minimum		8		Minimum		2
	Maximum		195		Maximum		156		Maximum		168		Maximum		200
	Percentiles	25	35		Percentiles	25	31		Percentiles	25	80		Percentiles	25	40
		50	80			50	79			50	120			50	100
		75	100			75	100			75	120			75	120
RCOC	N	Valid	331	WV	N	Valid	208	WY	N	Valid	188	ALL	N	Valid	2126
	Mean		101		Mean		78		Mean		84		Mean		88
	Median		114		Median		80		Median		91		Median		100
	Minimum		3		Minimum		1		Minimum		3		Minimum		1
	Maximum		194		Maximum		200		Maximum		200		Maximum		200
	Percentiles	25	85		Percentiles	25	26		Percentiles	25	35		Percentiles	25	48
		50	114			50	80			50	91			50	100
		75	120			75	120			75	120			75	120

Table 23. Total Hours Spent in Non-Work Activities, by State (Source: Consumer Survey Supplement FY2005)

CT	N	Valid	41	ME	N	Valid	142	OK	N	Valid	41	PA	N	Valid	376
Mean			80	Mean			70	Mean			63	Mean			78
Median			80	Median			79	Median			48	Median			80
Minimum			6	Minimum			7	Minimum			8	Minimum			2
Maximum			222	Maximum			150	Maximum			160	Maximum			219
Percentiles	25		30	Percentiles	25		30	Percentiles	25		20	Percentiles	25		30
	50		80		50		79		50		48		50		80
	75		100		75		100		75		120		75		120
RCOC	N	Valid	268	WV	N	Valid	155	WY	N	Valid	114	ALL	N	Valid	1137
Mean			80	Mean			79	Mean			73	Mean			77
Median			86	Median			80	Median			50	Median			80
Minimum			2	Minimum			3	Minimum			4	Minimum			2
Maximum			180	Maximum			220	Maximum			260	Maximum			260
Percentiles	25		47	Percentiles	25		40	Percentiles	25		19	Percentiles	25		30
	50		86		50		80		50		50		50		80
	75		114		75		120		75		124		75		120

Table 24. Community Employment Indicators, by State (Source: Consumer Survey Supplement FY2005)

	Continuous employment				Benefits				Years at current job			
	% No	% Yes	% N/A	Tot N	% No	% Yes	% N/A	Tot N	Mean	MIN	MAX	Tot N
CT	38.8	56.1	5.1	98	68.2	26.1	5.7	88	5.9	0.3	30	80
ME	47.2	22.8	29.9	254	6.1	43.7	50.2	247	5.3	1.0	11	32
OK	17.7	82.3	0.0	124	89.3	10.7	0.0	122	2.7	0.8	14	120
PA	39.5	13.4	47.1	1159	34.9	3.0	62.1	1119	4.4	0.8	37	159
RCOC	20.8	65.6	13.6	125	59.5	21.4	19.0	126	3.5	0.8	18	96
WV	31.7	68.3	0.0	123	15.1	84.9	0.0	86	3.3	0.1	18	62
WY	36.0	17.4	46.7	403	19.6	3.2	77.2	403	3.0	0.2	12	59

Table 25. Percent of Respondents Enrolled in Public School, by State (Source: Consumer Survey Supplement FY2005)

People enrolled in public school system			
	% No	% Yes	N
CT	93.6	6.4	140
ME	97.8	2.2	278
OK	93.7	6.3	414
PA	94.9	5.1	1210
RCOC	91.9	8.1	619
WV	94.4	5.6	286
WY	100.0	0.0	403

Table 26. Funding Sources of Day/Vocational Services Received, by State (Source: Consumer Survey Supplement FY2005)

Agency pays for day/vocational services person receives						
	HCBS Waiver Program	State MR/DD Agency	Voc Rehab Agency	PAS/IRWE	Other	N/A
	% Yes	% Yes	% Yes	% Yes	% Yes	% Yes
CT	96.5	98.7	90.0	0.0	100.0	88.9
ME	0.0	0.0	0.0	0.0	0.0	0.0
OK	55.1	19.1	0.0	0.0	5.3	21.7
PA	45.0	12.7	1.8	0.5	13.3	27.9
RCOC	0.0	52.7	2.1	0.0	1.6	0.0
WV	23.1	98.9	96.2	98.9	94.8	95.1
WY	83.9	18.1	1.7	0.0	1.2	2.2

The following table displays employment indicators for the two states that submitted state data system information.
Note: these data are from FY2004.

Table 27. Average Monthly Earnings and Average Hours Worked per Month, by State
(Source: State Data Systems FY2004)

State	Category of employment	Average Monthly Wage	Average Hours Worked per Month	N of Consumers
VT	Facility Based Work Program	N/A	N/A	N/A
	Group Supported	N/A	N/A	N/A
	Individual Supported	\$338.81	46.10	766
WA	Facility Based Work Program	\$118.51	64.38	935
	Group Supported	\$290.77	72.17	1002
	Individual Supported	\$759.34	84.02	1606
	Competitive			
<i>Source: Washington Division of Developmental Disabilities Cost Benefit Analysis Report June 2004</i>				
^a For VT, the “Individual Supported” line includes both categories “Competitive” and “Individual Supported” employment.				

Consumer Outcomes: Community Inclusion

The Community Inclusion Sub-domain has the following concern statement: “People use integrated community services and participate in everyday community activities.” There is one indicator listed:

1. The proportion of people who participate in everyday integrated activities in their communities.

Seven items from the consumer survey are grouped together to create a composite “scale score” for Community Inclusion. All of these items are first “risk adjusted” using a logistic regression model to control for differences in respondent characteristics (e.g., level of MR, age, etc.) across states. The predicted values created by the logistic regression represent the “adjusted mean proportion” for each state. A separate regression analysis is performed for each item. The scale score is then computed by averaging the predicted values of all seven items.

The seven items look at whether or not people:

- Go shopping
- Go out on errands or appointments
- Go out for entertainment
- Go out to eat
- Go to religious services
- Go to clubs or community meetings
- Exercise or play sports

A scale can be considered a reliable measure if its internal consistency is ≥ 0.70 . The statistic that assesses the scale’s reliability is called Cronbach’s alpha. An internal reliability test of the Community Inclusion scale resulted in a Cronbach’s alpha = **0.86**. This result attests to the reliability of the scale. In other words, we can be fairly confident that all items are measuring the same dimension.

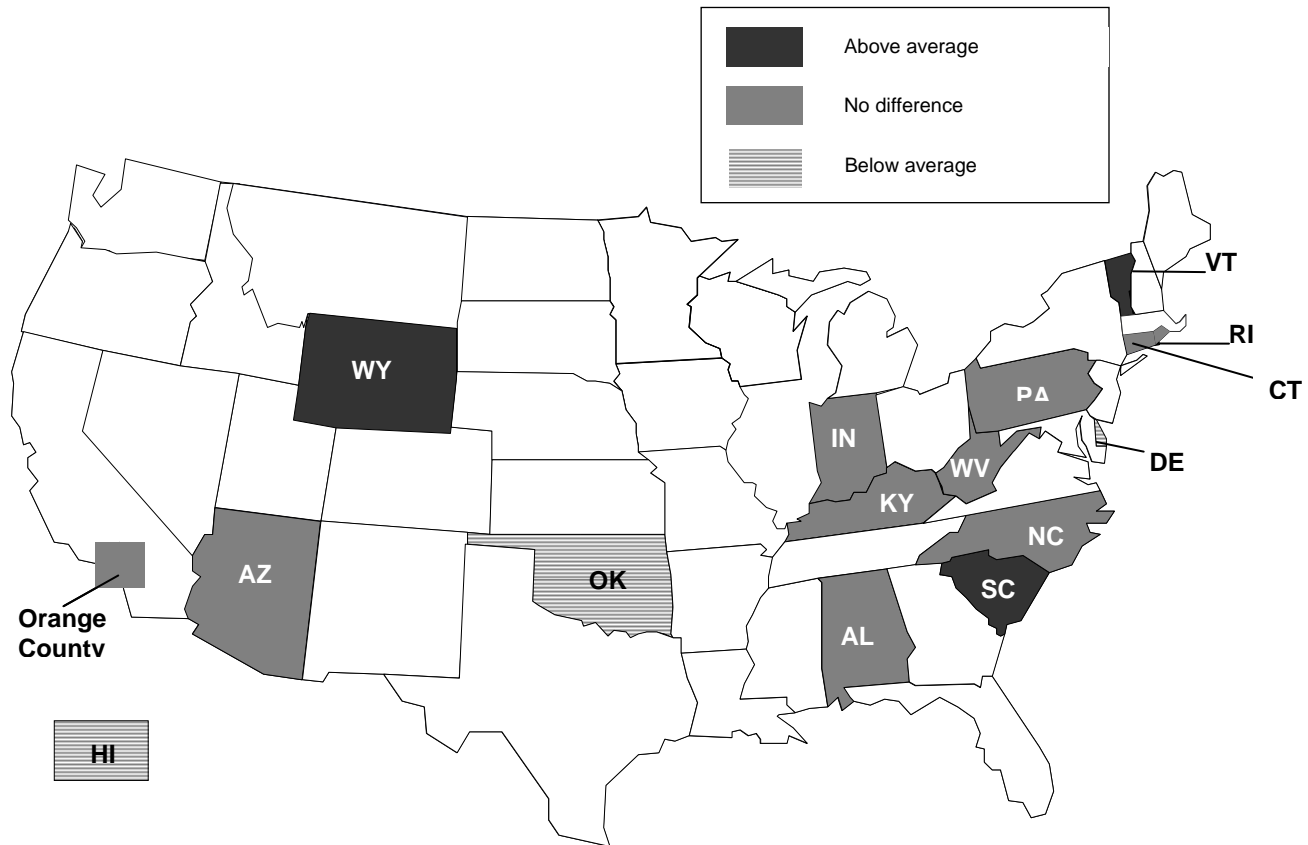
Each state’s scale score was compared with the average scale score across all other states (not including that state). The table on the right displays each state’s scale score compared with the average across all other states, and the last column indicates whether or not the state’s

score was significantly different from the average. A conservative cutoff point ($p \leq 0.01$) was used to determine significant differences. Figure 12 on the next page displays state performance on the Community Inclusion scale in a map format. Those states colored in black performed above average, those with horizontal stripes performed below average, and those in light grey were no different from the average.

Table 28. Community Inclusion Scale Scores by State, Compared to National Average

	State Scale Score	Average Across All Other States	Sig. at $p \leq 0.01$
VT	0.87	0.82	Yes
WY	0.85	0.82	Yes
SC	0.84	0.82	Yes
RCOC	0.84	0.82	Yes
CT	0.84	0.82	Yes
RI	0.83	0.82	No
KY	0.82	0.82	No
IN	0.82	0.82	No
PA	0.81	0.82	No
NC	0.81	0.82	No
WV	0.80	0.82	No
AL	0.80	0.82	Yes
HI	0.79	0.82	Yes
OK	0.78	0.82	Yes
DE	0.77	0.82	Yes

Figure 12. Community Inclusion: State Scale Scores Compared with National Average



Analysis of variance is a collection of techniques used to test for differences among more than two groups. Post hoc (multiple comparisons) tests provide information about which groups are different from each other. One such analysis, called Tukey's test, was performed to determine "homogeneous subsets" of results, i.e., groups of states that are not significantly different from one another. The following table displays the results of the Tukey's test. Subsets are arranged by column and labeled with a number at the top of each column. Scores that fall in the same subsets are not significantly different. For example, Hawaii's score of 0.79 spans across subsets 1 and 2. Therefore, its result is not significantly different from any of the other states that fall in subsets 1 or 2. It is, however, significantly different from Connecticut, the DD agency in Orange County, Wyoming, South Carolina and Vermont. Another way to interpret these results is to use the minimum significant difference, which is estimated at **0.03** for the Community Inclusion scale. Using the Hawaii example, any state with a score less than 0.76 or greater than 0.82 would be significantly different from Hawaii.

Table 29. Community Inclusion Scale Scores, by Subsets of States

Subset for alpha = .05							
State	N	1	2	3	4	5	6
DE	198	0.77					
OK	363	0.78	0.78				
HI	388	0.79	0.79				
WV	256	0.80	0.80	0.80			
AL	280	0.80	0.80	0.80			
NC	317	0.81	0.81	0.81	0.81		
PA	1000		0.81	0.81	0.81		
IN	716			0.82	0.82	0.82	
KY	317			0.82	0.82	0.82	
RI	329			0.83	0.83	0.83	
CT	277				0.84	0.84	0.84
RCOC	601				0.84	0.84	0.84
SC	152				0.84	0.84	0.84
WY	364					0.85	0.85
VT	180						0.87

The following seven tables display the results for each item that comprises the Community Inclusion Scale. Results are ordered from highest to lowest scores by state. The “adjusted” mean proportions are displayed. **“State average”** represents the average score across states. This figure is computed by adding the adjusted mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 95-98 of Appendix C.

Table 30. Proportion of people who go shopping

State	Valid N	Adjusted Mean Proportion (%)
VT	180	96.2
WY	364	95.9
CT	277	95.4
KY	317	94.9
RI	329	94.8
RCOC	601	94.5
SC	152	94.5
IN	716	94.5
NC	317	94.3
WV	256	94.0
AL	280	93.8
PA	1000	93.8
OK	363	93.8
HI	388	93.7
DE	198	92.5
State Average		94.4
Total	7148	94.4

Table 31. Proportion of people who go out on errands or appointments

State	Valid N	Adjusted Mean Proportion (%)
VT	180	97.5
WY	364	97.4
RCOC	601	97.2
RI	329	97.0
SC	152	97.0
CT	277	97.0
KY	317	96.9
IN	716	96.8
WV	256	96.6
PA	1000	96.5
NC	317	96.5
OK	363	96.2
AL	280	96.1
HI	388	95.8
DE	198	95.6
State Average		96.7
Total	5738	96.7

Table 32. Proportion of people who go out for entertainment

State	Valid N	Adjusted Mean Proportion (%)
VT	180	88.6
WY	364	88.5
CT	277	88.0
WV	256	87.9
KY	317	87.7
OK	363	87.6
NC	317	87.5
HI	388	87.5
RCOC	601	86.6
AL	280	86.5
SC	152	86.5
RI	329	85.9
IN	716	85.9
PA	1000	84.8
DE	198	84.7
State Average		86.9
Total	5738	86.6

Table 33. Proportion of people who go out to eat

State	Valid N	Adjusted Mean Proportion (%)
VT	180	95.2
WY	364	95.0
CT	277	94.7
SC	152	94.1
KY	317	94.0
RI	329	93.9
IN	716	93.5
RCOC	601	93.5
AL	280	93.2
NC	317	93.1
PA	1000	93.1
WV	256	92.7
OK	363	91.8
HI	388	91.7
DE	198	91.2
State Average		93.4
Total	5738	93.3

Table 34. Proportion of people who go to religious services

State	Valid N	Adjusted Mean Proportion (%)
SC	152	58.4
VT	180	57.3
RCOC	601	57.3
RI	329	57.1
IN	716	57.1
HI	388	56.9
WY	364	56.7
KY	317	56.3
CT	277	56.2
AL	280	56.0
PA	1000	55.7
DE	198	55.4
WV	256	55.0
NC	317	54.6
OK	363	54.5
State Average		56.3
Total	5738	56.3

Table 35. Proportion of people who go to clubs or community meetings

State	Valid N	Adjusted Mean Proportion (%)
RCOC	601	29.6
SC	152	28.5
PA	1000	28.4
RI	329	27.5
IN	716	26.5
DE	198	24.7
AL	280	24.1
VT	180	24.1
KY	317	23.8
WY	364	23.5
NC	317	23.4
CT	277	22.6
WV	256	21.4
OK	363	20.6
HI	388	20.4
State Average		24.6
Total	5738	25.3

Table 36. Proportion of people who exercise or play integrated sports⁹

State	Valid N	Adjusted Mean Proportion (%)
VT	180	49.4
WY	364	47.3
CT	277	45.6
KY	317	42.6
NC	317	42.4
SC	152	42.0
RI	329	41.7
RCOC	601	41.7
IN	716	41.5
WV	256	40.7
PA	1000	40.2
HI	388	39.6
OK	363	39.3
AL	280	39.0
DE	198	38.4
State Average		42.1
Total	5738	41.7

⁹ Indicator changed to reflect integrated activities only

Consumer Outcomes: Choice and Decision-Making

The Choice and Decision-Making Sub-domain has the following concern statement: “People make choices about their lives and are actively engaged in planning their services and supports.” The two indicators listed are:

1. The proportion of people who make choices about their everyday lives.
2. The proportion of people who report having been provided options about where to live and work.

The Consumer Survey includes eleven choice items. Two scales were created using the adjusted mean proportions of nine items. These two scales measure the first indicator. The first scale, called “Life Decisions” (previously called “Support-Related Choices”) is composed of five items. These items indicate whether people chose (or had some input in choosing):

- Place where they live (if not living with family)
- Staff who help at home
- Work or day activity
- Staff who help at work
- Case manager/service coordinator

The scale score is computed by averaging the predicted values of all five items. Internal consistency of the Life Decisions scale was high, with a Cronbach’s alpha of **0.92**.

The second scale, called “Everyday Choices” (previously “Personal Choices”) includes four items. These items indicate whether people choose (or have some input in choosing):

- People they live with (if not living with family)
- Daily schedule
- How to spend free time
- What to buy with spending money

The scale score is computed by averaging the predicted values of all four items. Internal consistency of the Everyday Choices scale was high, with a Cronbach’s alpha of **0.97**.

Each state’s scale score was compared with the average scale score across all other states (not including that state). The tables below display each state’s scale score compared with the average across all other states, and the last column indicates whether or not the state’s score was significantly different from the average. A conservative cutoff point ($p \leq 0.01$) was used to determine significant differences.

Figures 10 and 11 on the following pages display state performance on the Life Decisions and Everyday Choices scales in a map format. Those states colored in dark grey performed above average, those with horizontal stripes performed below average, and those in light grey were no different from the average.

**Table 37. Life Decisions Scale Scores
by State, Compared to National
Average**

	State Scale Score	Average Across All Other States	Sig. at p<=0.01
VT	0.827	0.662	Yes
WY	0.789	0.658	Yes
CT	0.722	0.664	Yes
IN	0.720	0.659	Yes
RCOC	0.710	0.662	Yes
KY	0.700	0.665	No
RI	0.682	0.666	No
PA	0.661	0.668	No
SC	0.644	0.667	No
NC	0.620	0.669	Yes
OK	0.608	0.671	Yes
WV	0.597	0.670	Yes
HI	0.559	0.675	Yes
DE	0.546	0.671	Yes
AL	0.528	0.674	Yes

**Table 38. Everyday Choices Scale
Scores by State, Compared to
National Average**

	State Scale Score	Average Across All Other States	Sig. At p<=0.01
VT	0.851	0.757	Yes
WY	0.809	0.757	Yes
RCOC	0.805	0.755	Yes
IN	0.800	0.754	Yes
RI	0.797	0.758	Yes
SC	0.794	0.759	No
CT	0.776	0.759	No
PA	0.775	0.757	No
KY	0.773	0.759	No
WV	0.741	0.761	No
NC	0.716	0.763	Yes
HI	0.684	0.766	Yes
DE	0.674	0.763	Yes
AL	0.667	0.765	Yes
OK	0.648	0.768	Yes

Figure 13. Life Decisions: State Scale Scores Compared with National Average

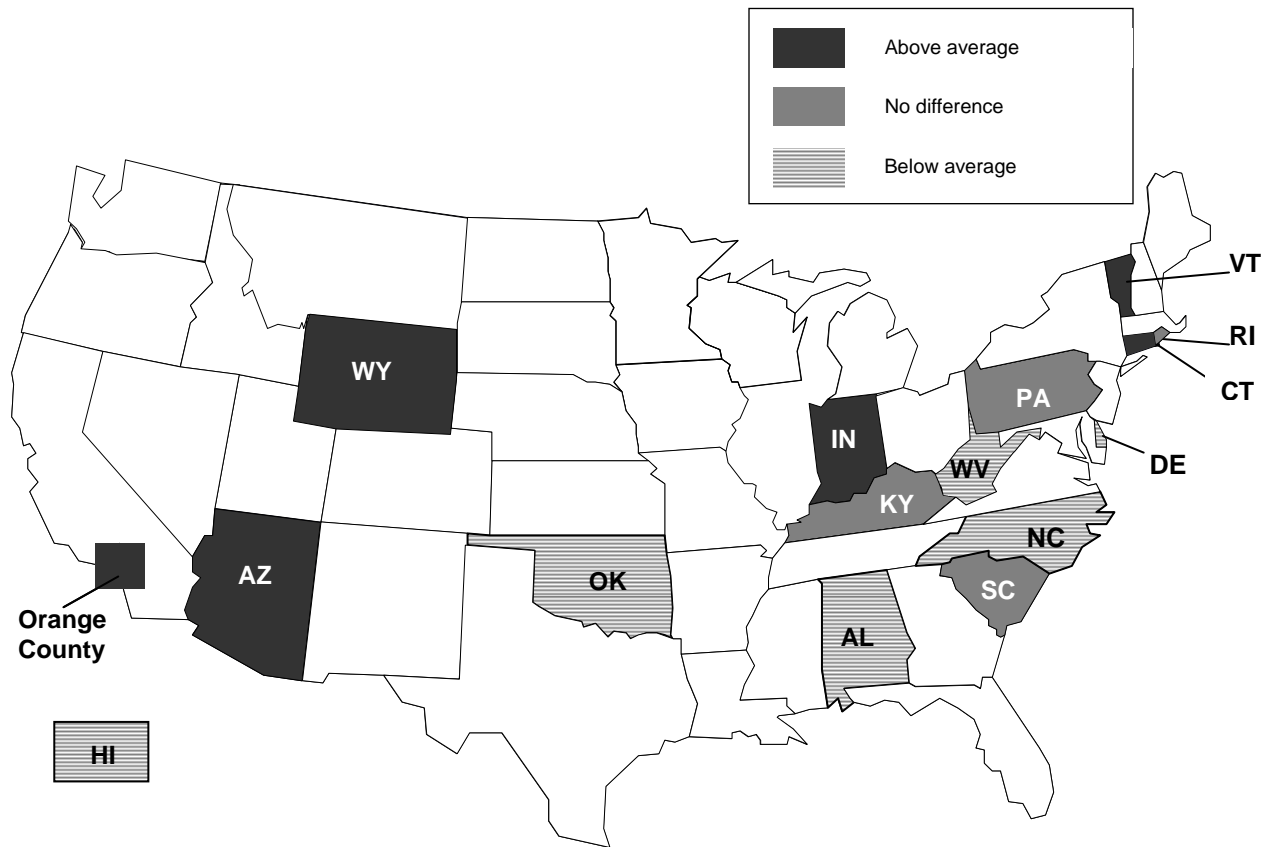
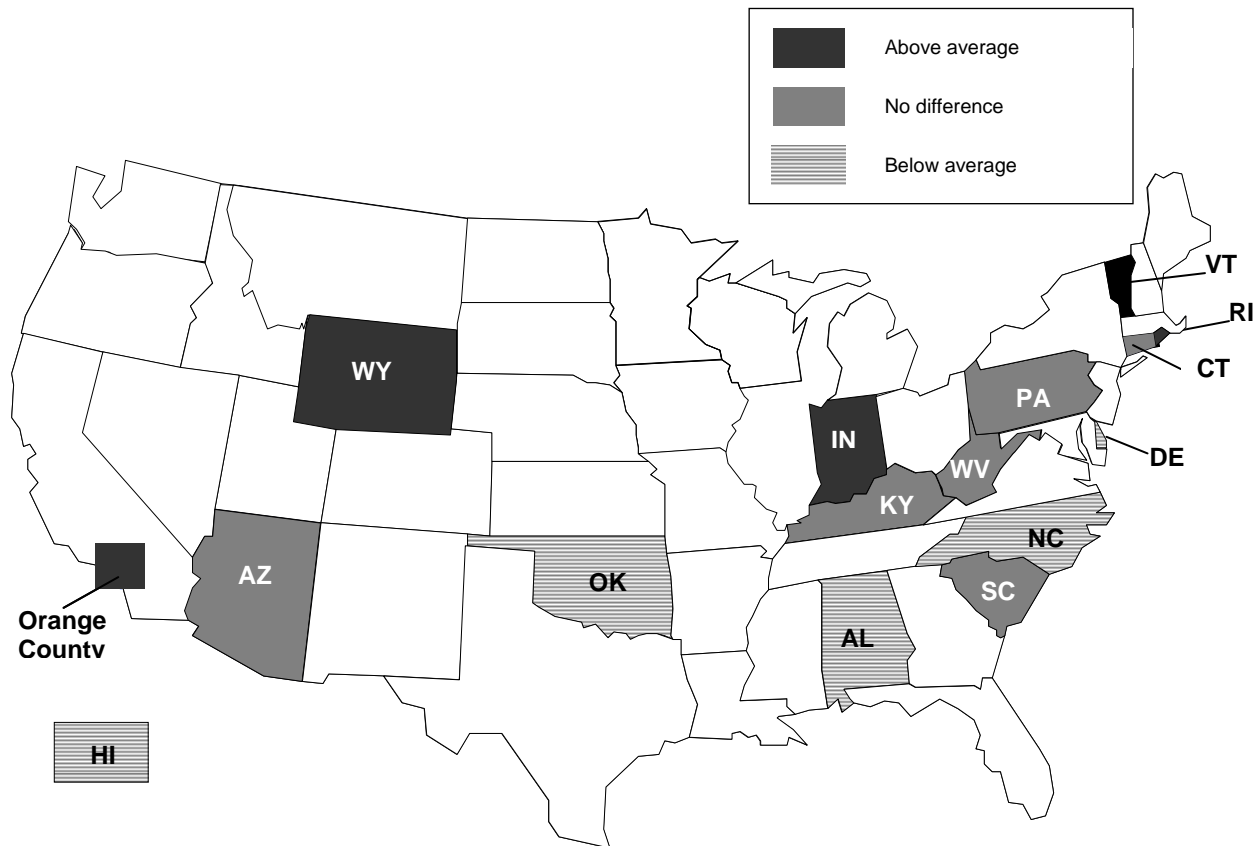


Figure 14. Everyday Choices: State Scale Scores Compared with National Average



Tukey's tests were also performed to determine which states were significantly different from one another on each scale. Scores that fall into the same subsets are not significantly different. For the Life Decisions scale the minimum significant difference is estimated at **0.08** and for the Everyday Choices scale the minimum significant difference is estimated at **.06**.

Table 39. Life Decisions Scale Scores, by Subsets of States

Subset for alpha = .05										
State	N	1	2	3	4	5	6	7	8	9
AL	280	0.53								
DE	198	0.55	0.55							
HI	388	0.56	0.56	0.56						
WV	256	0.60	0.60	0.60	0.60					
OK	363		0.61	0.61	0.61					
NC	317			0.62	0.62	0.62				
SC	152				0.64	0.64	0.64			
PA	1000				0.66	0.66	0.66	0.66		
RI	329					0.68	0.68	0.68		
KY	317						0.70	0.70		
RCOC	601						0.71	0.71		
IN	716							0.72	0.72	
CT	277							0.72	0.72	
WY	364								0.79	0.79
VT	180									0.83

Table 40. Everyday Choices Scale Scores, by Subsets of States

Subset for alpha = .05									
State	N	1	2	3	4	5	6	7	
OK	363	0.648							
AL	280	0.667	0.667						
DE	198	0.674	0.674						
HI	388	0.684	0.684	0.684					
NC	317		0.716	0.716	0.716				
WV	256			0.741	0.741	0.741			
KY	317				0.773	0.773	0.773		
PA	1000					0.775	0.775		
CT	277					0.776	0.776		
SC	152					0.794	0.794	0.794	
RI	329					0.797	0.797	0.797	
IN	716						0.800	0.800	
RCOC	601						0.805	0.805	
WY	364						0.809	0.809	
VT	180								0.851

The following eleven tables display the results for each choice item. The items that comprise the two choice scales are listed first. The last two items are not included in the scales, but relate to the second choice indicator. These two items are:

- Person looked at more than one home
- Person looked at more than one job

Results are ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the adjusted mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 99-104 of Appendix C.

Table 41. Proportion of people who chose place where they live

State	Valid N	Adjusted Mean Proportion (%)
VT	180	67.7
WY	364	65.1
IN	716	62.2
RCOC	601	62.0
CT	277	59.6
RI	329	59.5
PA	1000	58.4
KY	317	58.3
SC	152	57.4
NC	317	52.4
OK	363	50.9
WV	256	48.8
DE	198	48.2
HI	388	47.6
AL	280	46.7
State Average		56.3
Total	5738	57.2

Table 42. Proportion of people who choose staff who help them at home

State	Valid N	Adjusted Mean Proportion (%)
VT	37	70.1
WY	364	68.3
CT	277	65.6
IN	716	64.6
KY	317	64.4
RCOC	601	64.0
RI	329	62.9
WV	256	62.1
NC	317	61.6
PA	1000	61.5
OK	363	61.2
SC	152	60.8
HI	388	59.3
DE	198	58.3
AL	280	57.0
State Average		62.8
Total	5738	62.8

Table 43. Proportion of people who chose place of work or day activity

State	Valid N	Adjusted Mean Proportion (%)
VT	180	73.7
WY	364	71.5
IN	716	67.7
CT	277	67.4
RCOC	601	67.2
KY	317	66.3
RI	329	65.9
PA	1000	65.4
SC	152	63.1
NC	317	60.3
OK	363	58.9
WV	256	57.0
DE	198	55.6
AL	280	54.8
HI	388	54.7
State Average		63.3
Total	5738	64.0

Table 44. Proportion of people who choose staff who help them at work or day activity

State	Valid N	Adjusted Mean Proportion (%)
VT	180	69.2
WY	364	68.1
CT	277	67.1
KY	317	66.3
IN	716	65.8
RCOC	601	65.4
WV	256	65.2
RI	329	64.9
NC	317	64.8
SC	152	64.4
PA	1000	64.3
OK	363	63.9
HI	388	63.2
DE	198	62.9
AL	280	62.5
State Average		65.2
Total	5738	65.1

Table 45. Proportion of people who chose case manager/service coordinator

State	Valid N	Adjusted Mean Proportion (%)
VT	180	56.8
WY	364	55.7
CT	277	53.2
KY	317	52.4
IN	716	52.2
RCOC	601	51.7
OK	363	51.3
WV	256	50.5
RI	329	50.3
HI	388	50.0
NC	317	49.9
SC	152	49.1
PA	1000	49.0
DE	198	46.8
AL	280	46.6
State Average		51.0
Total	5738	51.0

Table 46. Proportion of people who choose people they live with

State	Valid N	Adjusted Mean Proportion (%)
VT	133	57.7
WY	304	54.8
IN	489	54.1
RCOC	373	52.2
SC	80	50.9
RI	206	50.1
CT	216	49.7
PA	662	48.9
KY	226	48.7
OK	358	46.0
WV	97	45.9
NC	223	45.2
DE	149	43.2
HI	218	40.5
AL	216	39.1
State Average		48.5
Total	3950	49.0

Table 47. Proportion of people who choose their daily schedule

State	Valid N	Adjusted Mean Proportion (%)
VT	180	90.5
WY	364	88.4
CT	277	85.3
IN	716	85.0
RCOC	601	85.0
RI	329	84.4
KY	317	83.8
PA	1000	83.1
SC	152	83.0
NC	317	79.7
WV	256	78.2
DE	198	76.4
OK	363	76.4
AL	280	76.2
HI	388	75.4
State Average		82.0
Total	5738	82.4

Table 48. Proportion of people who choose how to spend free time

State	Valid N	Adjusted Mean Proportion (%)
VT	180	96.1
WY	364	94.9
RCOC	601	93.6
RI	329	93.4
IN	716	93.3
CT	277	93.2
PA	1000	92.7
KY	317	92.6
SC	152	92.6
NC	317	89.2
AL	280	88.3
WV	256	87.8
DE	198	87.6
OK	363	86.8
HI	388	85.9
State Average		91.2
Total	5738	91.5

Table 49. Proportion of people who choose what to buy with spending money

State	Valid N	Adjusted Mean Proportion (%)
VT	180	95.7
WY	364	94.1
RCOC	601	92.1
IN	716	92.0
RI	329	91.7
CT	277	91.6
KY	317	91.2
PA	1000	90.
SC	152	90.6
NC	317	86.1
WV	256	85.3
AL	280	84.4
OK	363	84.3
DE	198	83.6
HI	388	82.5
State Average		89.1
Total	5738	89.5

Table 50. Proportion of people who looked at more than one home

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	301	56.1
IN	416	54.8
RCOC	246	46.7
CT	157	37.6
NC	190	37.4
RI	121	33.9
DE	124	29.8
OK	279	29.4
WV	87	28.7
AL	224	27.2
ME	191	26.2
KY	222	25.7
PA	561	24.2
HI	197	22.8
SC	222	6.3
State Average		32.5
Total	3538	33.6

Table 51. Proportion of people who looked at more than one job

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	247	70.0
DE	156	42.9
IN	532	41.7
OK	271	41.3
CT	205	41.0
NC	248	39.5
RI	157	38.2
RCOC	381	35.7
ME	177	33.3
KY	318	31.1
HI	246	29.7
WV	193	26.4
PA	988	20.5
AL	264	5.7
SC	386	5.4
State Average		33.5
Total	4769	30.9

Consumer Outcomes: Relationships

The Relationships Sub-domain has the following concern statement: “People have friends and relationships.” There are four indicators listed in this sub-domain:

1. The proportion of people who have friends and caring relationships with people other than support staff and family members.
2. The proportion of people who have a close friend, someone they can talk to about personal things.
3. The proportion of people who are able to see their families and friends when they want.
4. The proportion of people who feel lonely.

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 105-107 of Appendix C.

Table 52. Proportion of people who report having friends and caring relationships with people other than support staff and family members

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
OK	204	92.6
ME	187	90.4
WY	269	85.5
KY	317	82.6
RI	276	81.5
RCOC	454	80.0
CT	260	79.6
IN	642	77.7
VT	151	73.5
AL	199	70.4
WV	151	68.2
HI	228	66.7
NC	292	64.4
DE	131	64.1
PA	970	62.4
SC	360	15.6
State Average		72.2
Total	5091	70.4

Table 53. Proportion of people who report having a close friend

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
ME	178	94.9
KY	316	93.7
HI	215	92.6
WY	269	91.8
CT	255	89.8
OK	206	89.3
IN	612	88.4
VT	153	86.9
PA	938	85.5
AL	201	83.1
NC	292	81.2
WV	151	79.5
RI	270	78.5
SC	356	78.1
RCOC	456	77.9
DE	123	76.4
State Average		85.5
Total	4991	85.4

Table 54. Proportion of people who are able to see their families when they want to

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
RI	249	94.4
PA	475	93.1
KY	296	86.1
WY	263	84.4
VT	125	84.0
WV	143	82.5
SC	333	81.7
IN	604	81.3
NC	276	79.3
CT	250	76.0
HI	199	73.9
ME	198	69.7
RCOC	408	69.6
OK	180	66.1
AL	190	62.6
DE	120	58.3
State Average		77.7
Total	4309	79.5

Table 55. Proportion of people who are able to see their friends when they want to

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	264	91.7
OK	197	90.9
RI	247	89.5
SC	288	89.2
KY	305	88.5
VT	141	87.2
IN	586	86.2
PA	835	86.2
ME	181	84.0
CT	234	82.9
WV	129	82.2
NC	247	77.3
RCOC	387	73.1
HI	210	69.0
AL	174	59.8
DE	121	27.3
State Average		79.1
Total	4546	81.9

Table 56. Proportion of people who feel lonely (often or sometimes)

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	265	26.5
VT	142	39.5
WV	149	40.3
RI	273	41.8
HI	218	42.2
CT	254	43.3
PA	939	43.4
IN	596	44.0
RCOC	448	45.5
AL	196	47.0
ME	198	49.0
NC	287	51.5
DE	121	52.1
SC	329	52.9
OK	196	54.6
KY	315	60.3
State Average		45.9
Total	4926	45.6

Consumer Outcomes: Satisfaction

The Satisfaction Sub-domain has the following concern statement: “People are satisfied with the services and supports received.” The indicators measured by the Consumer Survey are:

1. The proportion of people satisfied with where they live.
2. The proportion of people who are satisfied with their job or day program.
3. The proportion of people who are satisfied with their personal lives (new indicator in 2005-2006).

Results are presented below for each item, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on p. 108 of Appendix C.

Table 57. Proportion of people who report satisfaction with where they live

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
KY	316	94.6
HI	226	93.8
VT	187	90.9
AL	212	90.6
RI	291	90.4
WV	155	89.7
WY	270	89.6
PA	1008	89.3
RCOC	462	89.2
IN	654	89.1
OK	208	88.5
CT	266	87.6
NC	298	86.2
DE	133	84.2
ME	208	82.7
SC	361	76.7
State Average		88.3
Total	5255	88.4

Table 58. Proportion of people who report satisfaction with their work/day program

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	202	98.5
VT	120	96.7
KY	299	95.3
OK	179	93.3
HI	168	92.9
WV	126	92.9
IN	540	92.4
SC	323	92.3
CT	248	91.1
PA	803	89.8
RI	275	89.5
AL	208	88.9
NC	222	88.3
ME	182	85.2
RCOC	397	84.4
DE	129	79.1
State Average		90.7
Total	4421	90.5

Table 59. Proportion of people who report satisfaction with their personal life

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	270	89.3
KY	314	88.2
SC	274	84.7
WV	153	84.3
CT	267	83.5
RI	281	81.1
AL	211	79.1
OK	202	78.7
RCOC	455	78.2
PA	990	73.4
NC	294	73.1
DE	131	64.1
State Average		79.8
Total	3842	79.1

System Performance: Service Coordination

The Service Coordination Sub-domain has the following concern statement: “Service Coordinators are accessible, responsive, and support the person’s participation in service planning.” The Consumer Survey measures three indicators related to service coordination:

1. The proportion of people reporting that service coordinators help them get what they need.
2. The proportion of people who know their service coordinators.
3. The proportion of people who report that their service coordinators asked about their preferences.

Results are presented below for each Service Coordination item, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 109-110 of Appendix C.

Table 60. Proportion of people who report that their service coordinators help them get what they need

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	260	95.8
KY	301	93.7
RI	240	92.5
VT	131	91.6
IN	494	91.5
SC	295	85.1
OK	186	83.9
RCOC	359	83.8
CT	199	83.4
NC	253	81.8
ME	153	81.7
HI	165	80.0
WV	134	79.1
PA	776	76.9
AL	137	75.2
DE	76	69.7
State Average		84.1
Total	4159	84.7

Table 61. Proportion of people who report that they know their case manager

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	266	97.4
OK	204	95.1
KY	313	94.9
NC	277	89.9
RI	278	89.6
VT	146	88.4
PA	928	85.6
WV	151	84.8
SC	328	80.8
RCOC	448	80.1
IN	604	77.2
CT	264	73.1
ME	188	72.3
HI	225	67.1
AL	197	62.4
DE	122	62.3
State Average		81.3
Total	4939	82.4

Table 62. Proportion of people who report that their case manager asks them what's important

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	260	96.5
KY	302	94.0
ME	149	90.6
RI	245	88.2
AL	135	85.9
IN	479	85.4
SC	283	80.6
HI	163	79.8
NC	256	79.3
VT	129	79.1
CT	203	76.8
RCOC	371	76.5
WV	129	76.0
OK	186	73.1
PA	786	72.9
DE	80	60.0
State Average		80.9
Total	4156	81.1

System Performance: Access

The Access Sub-domain has the following concern statement: “Publicly-funded services are readily available to individuals who need and qualify for them.” There are three Access indicators measured by the Consumer Survey:

1. The proportion of people reporting that they received support to learn or do something new in the past year.
2. The proportion of people who report having adequate transportation when they want to go somewhere.
3. The rate at which people report that “needed” services were not available.

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 111-112 of Appendix C.

Table 63. Proportion of people who report that needed services were not available

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WV	286	42.0
DE	223	39.5
RI	374	33.7
IN	789	24.7
NC	412	22.1
RCOC	600	21.1
PA	952	17.6
HI	390	14.1
CT	289	13.9
OK	413	11.1
SC	497	10.2
VT	146	9.6
ME	282	8.5
AL	375	8.2
KY	342	7.6
WY	401	3.9
State Average		18.0
Total	6771	18.0

Table 64. Proportion of people reporting that they received help to reach goals

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	269	97.8
SC	359	93.0
KY	123	84.6
NC	282	83.3
AL	197	82.7
ME	199	81.9
DE	125	81.6
VT	150	80.0
RI	269	78.1
OK	200	78.0
IN	587	77.9
RCOC	440	76.6
WV	150	76.0
CT	253	72.7
HI	217	68.2
PA	263	65.8
State Average		79.9
Total	4083	79.9

Table 65. Proportion of people who report having adequate transportation when they want to go somewhere

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
HI	227	95.2
WY	269	94.4
VT	153	90.8
SC	360	90.3
CT	264	88.6
ME	205	86.3
OK	205	86.3
WV	151	86.1
RI	271	85.6
IN	649	84.9
PA	990	84.9
RCOC	447	80.8
NC	289	76.8
KY	313	76.7
AL	205	52.7
DE	124	27.4
State Average		80.5
Total	5122	82.8

Health, Welfare, and Rights: Safety

The Safety Sub-domain has the following concern statement: “People are safe from abuse, neglect, and injury.” There is one Safety indicator measured with the Consumer Survey:

1. The proportion of people who report that they feel safe in their home and neighborhood.

Results are presented below for the two items related to this indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on p. 113 of Appendix C.

Table 66. Proportion of people who report that they feel safe in their home

State	Valid N	Mean Proportion (%)
WY	269	98.1
VT	154	97.4
RI	289	90.0
HI	224	88.8
IN	629	87.9
CT	256	85.9
NC	290	84.8
AL	205	83.9
OK	206	82.5
PA	974	82.5
RCOC	454	82.4
WV	156	80.1
KY	312	79.8
ME	198	74.2
DE	129	73.6
SC	331	72.8
State Average		84.0
Total	5076	84.1

Table 67. Proportion of people who report that they feel safe in their neighborhood

State	Valid N	Mean Proportion (%)
WY	269	98.5
VT	142	94.4
RI	281	91.8
IN	624	85.1
DE	126	84.9
HI	222	84.2
PA	946	83.7
WV	155	81.9
CT	252	81.7
AL	201	81.1
NC	286	81.1
KY	309	80.9
ME	198	80.8
OK	206	79.6
RCOC	448	77.2
SC	328	70.7
State Average		83.6
Total	4993	83.2

Health, Welfare & Rights: Health

The Health Sub-domain has the following concern statement: “People secure needed health services.” There are four Health indicators collected with the Background Information section of the Consumer Survey:

1. The proportion of people who have had a physical exam in the past year.
2. The proportion of women who have had a GYN exam in the past year.
3. The proportion of people who have had a routine dental exam in the past six months.
4. The proportion of people who maintain healthy habits in such areas as smoking, weight, and exercise.

Three questions were added to the survey in 2004-2005 to measure the fourth indicator. These items were adapted from a supplemental survey on health status developed in the state of North Carolina. The results can be compared to national data collected on the National Health Interview Survey (NHIS).

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 114-116 of Appendix C.

Table 68. Proportion of people who had a physical exam in the past year

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
OK	414	97.8
WV	289	97.6
IN	810	96.3
ME	292	95.5
KY	503	94.8
AL	392	88.8
NC	461	88.3
WY	403	87.3
CT	413	86.7
PA	1339	84.7
RI	383	80.9
VT	373	78.3
DE	223	75.3
SC	530	73.6
HI	406	58.9
RCOC	619	58.2
State Average		83.9
Total	7850	83.8

Table 69. Proportion of women who had a gynecological exam in the past year

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
KY	219	78.1
WY	190	75.3
AL	164	67.7
NC	189	67.7
OK	153	66.0
CT	195	64.1
IN	348	64.1
DE	90	60.0
RI	171	51.5
PA	597	49.7
SC	221	46.2
WV	131	38.9
HI	199	31.7
RCOC	271	24.7
State Average		56.1
Total	3138	54.9

Table 70. Proportion of people who had a routine dental exam in the past six months

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	403	75.7
IN	809	67.1
CT	415	66.7
WV	289	66.1
ME	278	62.2
DE	224	59.8
OK	414	56.5
KY	488	54.9
VT	373	54.7
NC	459	53.6
RI	384	49.0
PA	1335	45.6
AL	390	44.4
SC	530	39.2
RCOC	619	27.9
HI	406	15.3
State Average		52.0
Total	7816	51.0

Table 71. Proportion of people for whom weight is a concern (underweight or overweight)

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
SC	185	26.0
RCOC	619	27.1
DE	224	27.3
KY	502	27.7
VT	373	29.5
PA	1341	30.1
NC	447	30.4
CT	412	33.0
WY	403	33.0
RI	383	34.9
OK	414	36.5
WV	289	41.8
AL	395	44.6
State Average		32.5
Total	5987	32.0

Table 72. Proportion of people who smoke or chew tobacco

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
RCOC	619	2.6
DE	223	4.9
CT	414	5.3
RI	384	7.3
SC	185	7.6
WY	403	8.7
AL	395	9.4
PA	1344	9.4
OK	414	10.4
KY	496	11.7
VT	373	12.3
NC	453	16.6
WV	386	9.4
State Average		8.9
Total	5989	9.0

Table 73. Proportion of people who are physically inactive

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
RCOC	619	12.9
SC	185	17.
VT	373	18.2
AL	399	18.3
OK	414	20.5
CT	415	21.0
RI	384	21.1
PA	1342	23.
WY	403	23.6
WV	289	26.6
NC	443	27.5
KY	497	29.4
DE	224	31.7
State Average		22.4
Total	5987	22.1

Health, Welfare & Rights: Medications

The Medications Sub-domain has the following concern statement: “Medications are managed effectively and appropriately.” There is one indicator collected using the Background Information section of the Consumer Survey:

1. The proportion of people taking medications for mood disorders, anxiety, behavior problems, or psychotic disorders.

Results are presented below for this indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on p. 117 of Appendix C.

Table 74. Proportion of people receiving psychotropic¹⁰ medications

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
NC	261	69.0
KY	509	58.0
WV	288	52.4
OK	413	50.1
CT	406	50.0
RI	362	48.6
AL	398	47.5
PA	1271	47.3
WY	403	43.9
IN	783	43.6
RCOC	619	41.0
DE	211	40.8
SC	512	38.7
HI	401	20.9
State Average		53.4
Total	6837	54.0

¹⁰ Results include medication taken for mood, anxiety, behavioral or psychotic disorders. The last category (psychotic disorders) was added in the 2005-2006 version of the survey.

NC is not included because of too many missing values.

Health, Welfare & Rights: Respect/Rights

The Respect/Rights Sub-domain has the following concern statement: “People receive the same respect and protections as others in the community.” There are five indicators measured by the Consumer Survey:

1. The proportion of people who have an advocate or someone who speaks on their behalf.
2. The proportion of people whose basic rights are respected by others.
3. The proportion of people who have participated in activities of self-advocacy groups or other groups that address rights.
4. The proportion of people who report satisfaction with the amount of privacy they have.
5. The proportion of people indicating that most support staff treat them with respect.

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 118-122 of Appendix C.

Table 75. Proportion of people reporting that they have an advocate or someone who speaks on their behalf

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
OK	165	97.6
WY	191	96.9
RI	229	94.3
HI	141	92.9
CT	159	91.2
IN	304	90.5
VT	77	89.6
ME	143	89.5
KY	176	87.5
NC	224	87.5
SC	294	86.4
WV	107	83.2
DE	95	80.0
RCOC	275	58.9
AL	94	51.1
State Average		85.1
Total	2674	85.6

Table 76. Proportion of people reporting that their mail is opened without permission

State	Valid N	Adjusted Mean Proportion (%)
VT	180	11.4
WY	364	12.1
CT	277	13.4
RCOC	601	13.4
IN	716	13.6
RI	329	13.7
PA	1000	13.8
KY	317	13.9
SC	152	15.9
NC	317	16.7
OK	363	17.4
AL	280	17.9
DE	198	18.5
WV	256	18.6
HI	388	19.5
State Average		15.3
Total	5738	14.9

Table 77. Proportion of people who report that they have some restrictions on being alone with guests

State	Valid N	Adjusted Mean Proportion (%)
VT	180	11.3
WY	364	12.3
IN	716	12.9
RI	329	13.0
PA	1000	13.1
RCOC	601	13.5
CT	277	13.9
KY	317	14.1
SC	152	15.3
DE	198	16.3
NC	317	16.4
OK	363	17.0
AL	280	17.4
HI	388	17.5
WV	256	18.5
State Average		14.8
Total	5738	14.4

Table 78. Proportion of people reporting that there are restrictions on their use of the phone

State	Valid N	Adjusted Mean Proportion (%)
VT	180	8.3
WY	364	8.7
IN	716	9.1
RCOC	601	9.1
RI	329	9.4
CT	277	9.5
PA	1000	9.6
SC	152	9.7
KY	317	9.7
HI	388	10.1
DE	198	10.3
NC	317	10.4
OK	363	10.6
AL	280	10.9
WV	256	11.1
State Average		9.8
Total	5738	9.7

Table 79. Proportion of people reporting that other people enter their home without permission

State	Valid N	Adjusted Mean Proportion (%)
HI	220	9.3
RCOC	461	9.4
IN	599	9.5
SC	114	9.5
RI	257	9.6
OK	174	9.7
VT	180	9.7
WV	145	9.7
AL	150	9.9
NC	221	9.9
PA	775	10.0
WY	260	10.1
DE	119	10.2
KY	292	10.6
CT	244	10.6
State Average		9.8
Total	4211	9.8

Table 80. Proportion of people report that other people enter their bedroom without permission

State	Valid N	Adjusted Mean Proportion (%)
WY	260	14.6
VT	180	14.9
OK	174	15.1
CT	244	15.8
RCOC	461	16.0
IN	599	16.1
NC	221	16.2
WV	145	16.2
KY	292	16.4
RI	257	16.5
PA	775	16.7
HI	220	17.0
AL	150	18.0
DE	119	18.3
SC	114	18.6
State Average		16.4
Total	4211	16.3

Table 81. Proportion of people who have attended activities of self-advocacy groups

State	Valid N	Adjusted Mean Proportion (%)
VT	180	28.2
WY	364	28.1
CT	277	27.1
KY	317	26.7
OK	363	26.5
IN	716	26.4
HI	388	24.9
RCOC	601	24.9
RI	329	24.7
WV	256	24.3
NC	317	24.2
PA	1000	24.0
SC	152	23.0
AL	280	22.8
DE	198	22.5
State Average		25.2
Total	5738	25.2

Table 82. Proportion of people reporting they can be alone (have privacy)

State	Valid N	Adjusted Mean Proportion (%)
SC	114	93.1
RCOC	461	93.0
RI	257	92.9
DE	119	92.9
AL	150	92.9
PA	775	92.9
IN	599	92.8
OK	174	92.8
KY	292	92.3
HI	220	92.3
NC	221	92.3
WV	145	92.1
CT	244	91.8
VT	180	91.6
WY	260	91.5
State Average		92.5
Total	4211	92.6

Table 83. Proportion of people reporting that most day support staff treat them with respect

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	192	97.9
CT	230	97.8
RI	263	97.0
VT	97	96.9
WV	116	96.6
OK	172	95.3
IN	540	95.2
AL	207	94.7
KY	300	94.3
ME	165	93.3
RCOC	361	92.5
NC	211	91.5
DE	123	91.1
PA	656	89.5
SC	333	85.9
HI	166	83.1
State Average		93.3
Total	4132	92.8

Table 84. Proportion of people reporting that most residential support staff treat them with respect

<i>State</i>	<i>Valid N</i>	<i>Mean Proportion (%)</i>
WY	229	96.9
OK	206	94.2
RI	181	93.4
DE	75	93.3
ME	195	92.3
WV	112	92.0
KY	245	91.4
NC	218	91.3
PA	498	91.2
IN	421	91.0
CT	221	89.6
VT	63	88.9
HI	104	88.5
AL	153	85.6
RCOC	312	81.4
SC	265	68.7
State Average		89.4
Total	3498	88.9

Appendix A: Rules for Recoding and Combining Variables to Compute Core Indicators

Table 85. Background Information Variables Used to Adjust Outcomes

<i>BI Item #</i>	<i>Variable Name</i>	<i>Recode or Collapse?</i>
BI-3	DOB	Create AGE variable
BI-4	GENDER	As is
BI-7	LGLSTAT	Collapse into 2 categories: a) independent and b) not independent
BI-10	LEVELMR	Collapse into 3 categories: a) No MR + Mild ; b) Moderate ; c) Severe + Profound
BI-11	DXMIPD, DXAUTISM, DXCP, DXCHEMDP, DXOTHER	Use each disability as separate adjustment variable. As is
BI-13	EXPRESS	Collapse into 2 categories: a) verbal and b) non-verbal
BI-14	MOBILITY	As is
BI-15	VISION	Collapse into 2 categories: a) has vision problems and b) sees well

Table 86. Outcome Variables -- Rules for Analysis

<i>Survey Item #</i>	<i>Variable Name</i>	<i>Recode or Collapse?</i>	<i>Risk Adjust?</i>
Q1	LIKEWORK	Collapse <i>In-between</i> (1) and <i>Yes</i> (2)	
Q2	STAFNICE	Collapse <i>In-between</i> (1) and <i>No</i> (0)	
Q3	LIKEHOME	Collapse <i>Yes</i> (2) and <i>In-between</i> (1)	
Q4	BEALONE	As is	YES
Q5	AFRAIDHM	Collapse <i>Sometimes</i> (1) and <i>Yes</i> (2)	
Q6	AFRAIDNH	Collapse <i>Sometimes</i> (1) and <i>Yes</i> (2)	
Q7	HOMESTAF	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q8-9	ENTERHM, ENTERBRM	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	YES
Q11	HASFRNDS	Collapse <i>No</i> (0) and <i>Yes - staff or family</i> (1)	
Q10	BESTFRND	As is	
Q12	SEEFRNDS	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q13	LONELY	Collapse <i>Sometimes</i> (1) and <i>Often</i> (2)	
Q14	SEEFAMILY	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q15	KNOWSCM	Collapse <i>Maybe</i> (1) and <i>Yes</i> (2)	
Q17	HELPSGET	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q16	ASKIMPOR	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q18	HASADVOC	Collapse <i>Maybe</i> (1) and <i>No</i> (0)	
Q19	HELPGOAL	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	YES
Q20	NEWGOAL	As is	
Q21	HAPPY	As is	
Q22	TRANSPOR	Collapse <i>No</i> (0) and <i>Sometimes</i> (1)	YES
Q23	STFPAY	Not included in report	
Q24	BUDGET	Not included in report	

<i>Survey Item #</i>	<i>Variable Name</i>	<i>Recode or Collapse?</i>	<i>Risk Adjust?</i>
Q28-33	SHOPPING, ERRANDS, ENTERTAN, EATOUT, RELIGION, CLUBS	As is	YES
Q34	SPORTS	Collapse <i>Non-integrated (1) and No exercise (0)</i>	YES
Q35, Q37- Q41, Q43- Q45	CHOSHOME, ROOMATES, CHSSTAFF, SCHEDULE, FREETIME, CHOOSJOB, CHSJBSTF, CHOOSBUY CHOOSCM	Collapse <i>Person had some input (1) and Person chose without help (2)</i>	YES
Q36, Q42	NUMHOME, NUMJOBS	Collapse <i>Visited one place only (1) and Did not visit (0)</i>	
Q46-48	MAIOPEN, ALONEGST, USEPHONE	As is	YES
Q49	SELSADVO	Collapse <i>Yes (2) and Had opportunity but chose not to (1)</i>	YES
Q50	SERVED	Collapse <i>No (0) and Sometimes (1)</i>	

Appendix B: Services and Supports Received

Service Coordination/Case Management

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	1.3	2.4	4.5	0.7	1.2	0.6	8.6	1.2	1.4	0.0	7.3	2.6	9.1	1.0	0.0	2.4	2.8
% Yes	98.7	97.3	95.5	99.3	98.4	99.4	90.3	98.8	98.3	100.0	91.7	95.3	90.9	99.0	100.0	97.2	96.9
% DK	0.0	0.2	0.0	0.0	0.4	0.0	1.1	0.0	0.2	0.0	1.0	2.1	0.0	0.0	0.0	0.4	0.3
N	396	414	224	406	810	484	443	414	1330	619	384	530	373	289	403	7519	

Voc - Supported Employment

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	97.0	76.5	79.9	95.1	84.7	3.5	74.3	89.6	86.9	85.0	76.6	72.8	57.5	81.0	79.4	81.5	76.0
% Yes	3.0	23.0	19.6	4.9	15.1	96.5	24.2	10.4	11.4	14.9	22.7	11.1	42.5	18.0	20.6	16.7	22.5
% DK	0.0	0.5	0.4	0.0	0.2	0.0	1.5	0.0	1.7	0.2	0.8	16.0	0.0	1.0	0.0	1.8	1.5
N	365	374	224	406	810	57	389	414	1210	619	384	530	372	289	403	6846	

Voc - Group Employment

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	94.2	71.4	80.4	99.8	98.5	8.3	92.5	80.9	94.9	86.6	75.3	70.0	98.9	97.9	88.6	88.8	82.5
% Yes	5.8	28.0	17.9	0.2	1.2	91.7	5.3	19.1	3.3	13.2	22.9	14.2	1.1	1.7	11.4	9.3	15.8
% DK	0.0	0.5	1.8	0.0	0.2	0.0	2.1	0.0	1.9	0.2	1.8	15.8	0.0	0.3	0.0	1.9	1.6
N	365	378	224	406	810	12	375	414	1189	619	384	530	372	289	403	6770	

Voc - Facility Based

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	71.0	75.5	60.3	95.6	48.3	0.5	59.9	54.1	68.7	79.2	51.3	44.9	99.7	87.2	44.4	63.9	62.7
% Yes	29.0	24.2	38.8	4.4	51.1	99.5	39.5	45.9	29.8	20.7	47.9	43.0	0.3	12.1	55.6	34.7	36.1
% DK	0.0	0.3	0.9	0.0	0.6	0.0	0.5	0.0	1.6	0.2	0.8	12.1	0.0	0.7	0.0	1.4	1.2
N	366	376	224	406	810	212	397	414	1219	619	384	530	372	289	403	7021	

Non-Voc Day Services

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	31.0	67.7	56.3	36.2	52.0	0.5	61.8	97.3	65.9	79.0	70.6	58.7	42.6	54.3	74.9	59.7	56.6
% Yes	68.7	31.5	42.0	63.8	46.2	99.5	37.0	2.7	32.1	20.8	27.3	26.0	57.4	45.3	25.1	38.3	41.7
% DK	0.3	0.8	1.8	0.0	1.9	0.0	1.3	0.0	2.0	0.2	2.1	15.3	0.0	0.3	0.0	2.0	1.7
N	393	387	224	406	810	220	387	414	1217	619	384	530	373	289	403	7056	

Community Participation

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	39.7	46.7	37.5	59.9	24.7	0.4	38.2	88.9	58.0	75.1	41.1	60.0	N/A	29.1	0.0	46.4	42.8
% Yes	60.3	51.8	59.4	40.1	73.5	99.6	59.8	11.1	38.8	23.9	57.0	18.1	N/A	70.2	100.0	50.6	54.5
% DK	0.0	1.5	3.1	0.0	1.9	0.0	2.0	0.0	3.2	1.0	1.8	21.9	N/A	0.7	0.0	3.1	2.7
N	368	390	224	406	810	247	398	414	1216	619	384	530	N/A	289	403	6698	

Assistive Technology

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	98.6	80.2	58.0	95.6	69.4	2.0	81.8	67.9	89.1	93.4	88.3	63.6	N/A	76.5	99.3	81.8	76.0
% Yes	1.4	18.5	35.7	4.4	27.7	98.0	16.0	32.1	8.1	6.1	9.9	20.0	N/A	22.1	0.7	15.3	21.5
% DK	0.0	1.3	6.3	0.0	3.0	0.0	2.1	0.0	2.8	0.5	1.8	16.4	N/A	1.4	0.0	2.9	2.5
N	365	379	224	406	810	50	374	414	1192	619	384	530	N/A	289	403	6439	

Clinical Services

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	66.4	38.2	39.5	96.3	51.5	1.0	41.3	23.4	65.8	78.7	46.9	54.5	57.5	27.3	70.0	55.4	50.6
% Yes	33.6	59.7	57.0	3.7	44.8	99.0	57.1	76.6	31.1	20.8	50.3	31.5	42.2	72.0	30.0	42.0	47.3
% DK	0.0	2.0	3.6	0.0	3.7	0.0	1.5	0.0	3.1	0.5	2.9	14.0	0.3	0.7	0.0	2.6	2.2
N	369	395	223	406	810	191	392	414	1212	619	384	530	372	289	403	7009	

Transportation

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	19.6	21.2	12.9	95.6	11.7	0.2	33.3	4.8	46.0	31.7	15.9	38.1	55.9	11.1	0.0	28.7	26.5
% Yes	80.4	77.5	83.9	4.4	87.0	99.8	65.4	95.2	51.4	68.3	83.1	46.4	44.1	88.2	100.0	69.3	71.7
% DK	0.0	1.3	3.1	0.0	1.2	0.0	1.2	0.0	2.6	0.0	1.0	15.5	0.0	0.7	0.0	2.0	1.8
N	387	387	224	406	810	445	408	414	1243	619	384	530	372	289	403	7321	

Respite

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	89.0	79.2	56.7	91.1	86.0	0.6	63.6	93.2	77.9	79.6	85.4	67.7	55.1	44.3	90.1	75.8	70.6
% Yes	10.7	18.7	32.1	8.9	10.1	98.8	34.9	6.5	19.5	19.9	12.8	18.1	44.9	54.7	9.9	21.4	26.7
% DK	0.3	2.1	11.2	0.0	3.8	0.6	1.5	0.2	2.7	0.5	1.8	14.2	0.0	1.0	0.0	2.8	2.7
N	363	375	224	406	810	160	393	414	1202	619	384	530	372	289	403	6944	

Enrolled In School System

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	99.7	94.6	91.8	95.6	91.2	16.7	90.6	94.4	93.7	91.6	97.1	77.9	N/A	94.5	87.6	91.9	86.9
% Yes	0.0	4.0	0.9	4.4	8.1	83.3	8.8	5.6	4.5	8.1	2.1	5.5	N/A	4.8	12.4	5.8	10.9
% DK	0.3	1.3	7.3	0.0	0.6	0.0	0.5	0.0	1.8	0.3	0.8	16.6	N/A	0.7	0.0	2.3	2.2
N	365	371	220	405	810	12	374	414	1198	619	384	530	N/A	289	403	6394	

Other Services And Supports

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	98.8	86.8	82.4	57.6	94.9	5.0	72.2	68.4	85.1	85.6	94.3	55.8	92.5	68.2	53.3	79.3	73.4
% Yes	0.6	6.0	3.4	36.5	1.5	95.0	18.0	31.6	8.9	13.6	4.2	9.1	7.5	8.7	46.7	13.6	19.4
% DK	0.6	7.2	14.2	5.9	3.6	0.0	9.8	0.0	6.0	0.8	1.6	35.1	0.0	23.2	0.0	7.1	7.2
N	341	319	148	406	810	20	266	414	1042	619	384	530	372	289	403	6363	

Home And Community Based Waiver

	AL	CT	DE	HI	IN	KY	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
ICF/MR	23.3	10.5	26.3	2.0	24.6	70.5	18.2	16.4	11.7	15.2	5.2	32.3	0.3	8.3	0.0	16.1	17.7
HCBS	75.2	67.4	33.0	81.5	45.8	13.0	26.2	79.2	44.2	40.7	62.0	53.8	99.7	86.9	100.0	57.9	60.6
DK	0.8	7.6	11.6	1.0	2.8	9.0	6.2	0.0	3.3	1.1	4.4	4.2	0.0	1.7	0.0	3.2	3.6
Other	0.8	14.5	29.0	15.5	26.8	7.5	49.4	4.3	40.8	43.0	28.4	9.8	0.0	3.1	0.0	22.8	18.2
Count	395	408	224	406	794	200	451	414	1319	619	384	530	320	289	403	7156	

Self-Directed Support Option

	AL	CT	DE	HI	IN	KY	ME	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	94.7	91.3	95.1	N/A	N/A	N/A	N/A	79.2	90.1	84.8	100.0	85.4	85.5	76.1	8.8	0.0	77.3	74.3
% Yes	4.3	7.5	3.6	N/A	N/A	N/A	N/A	17.0	9.9	11.3	0.0	8.1	8.4	19.8	89.8	100.0	20.2	23.3
% DK	1.0	1.2	1.3	N/A	N/A	N/A	N/A	3.8	0.0	3.9	0.0	6.5	6.0	4.0	1.4	0.0	2.5	2.4
N	396	412	224	N/A	N/A	N/A	N/A	453	414	1292	619	384	166	373	283	403	5419	

Individually Negotiated Budget

	AL	CT	DE	HI	IN	KY	ME	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	52.3	85.1	92.9	94.3	10.6	4.4	16.5	55.3	18.4	57.0	100.0	41.9	29.1	20.9	88.2	0.0	47.9	47.9
% Yes	46.4	12.3	5.4	5.7	87.2	94.4	76.8	38.2	80.9	37.3	0.0	24.5	54.5	72.7	9.7	100.0	46.6	46.6
% DK	1.3	2.6	1.8	0.0	2.2	1.2	6.7	6.4	0.7	5.7	0.0	33.6	16.4	6.4	2.1	0.0	5.5	5.4
N	394	390	224	406	810	251	285	421	414	1294	619	384	530	373	289	403	7487	

Person-Centered Planning

	AL	CT	DE	HI	IN	KY	ME	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	44.3	38.1	25.9	42.4	3.0	1.1	3.4	9.1	3.1	38.2	0.0	16.4	16.2	9.7	82.4	0.0	20.5	20.8
% Yes	51.4	60.1	72.3	57.4	95.8	98.6	96.6	88.6	96.9	58.8	100.0	58.9	78.5	89.0	15.2	100.0	76.5	76.1
% DK	4.3	1.7	1.8	0.2	1.2	0.3	0.0	2.3	0.0	3.0	0.0	24.7	5.3	1.3	2.4	0.0	2.9	3.0
N	395	404	224	406	810	368	292	438	414	1301	619	384	530	373	289	403	7650	

Fiscal Intermediary

	AL	CT	DE	HI	IN	KY	ME	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	98.7	89.9	98.2	100.0	86.3	37.7	83.9	85.3	100.0	89.7	100.0	66.4	80.6	62.7	97.6	100.0	88.9	86.1
% Yes	1.3	7.8	0.4	0.0	0.2	52.8	6.4	4.9	0.0	6.7	0.0	3.1	4.3	30.0	0.7	0.0	4.7	7.4
% DK	0.0	2.3	1.3	0.0	13.5	9.4	9.6	9.8	0.0	3.6	0.0	30.5	15.1	7.2	1.7	0.0	6.4	6.5
N	394	387	224	406	810	53	280	407	414	1294	619	384	530	373	289	403	7267	

Microboard To Manage Funds

	AL	CT	DE	HI	IN	KY	ME	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	99.7	96.1	97.8	100.0	86.7	74.2	91.0	93.4	100.0	96.8	100.0	69.5	86.6	N/A	97.9	100.0	93.8	92.7
% Yes	0.3	0.5	0.4	0.0	0.1	9.7	2.9	0.7	0.0	0.4	0.0	0.8	1.5	N/A	0.0	0.0	0.5	1.2
% DK	0.0	3.4	1.8	0.0	13.2	16.1	6.1	5.8	0.0	2.8	0.0	29.7	11.9	N/A	2.1	0.0	5.7	6.2
N	394	384	224	406	810	31	279	411	414	1295	619	384	530	N/A	289	403	6873	

Support Broker

	AL	CT	DE	HI	IN	KY	ME	NC	OK	PA	RCOC	RI	SC	VT	WV	WY	Total	State Average
% No	99.5	94.3	96.4	100.0	86.7	65.6	90.3	84.9	100.0	95.4	100.0	69.3	86.8	90.6	97.9	100.0	92.7	91.1
% Yes	0.5	3.1	1.3	0.0	0.0	21.9	3.6	9.5	0.0	1.1	0.0	0.8	0.9	3.2	0.0	0.0	1.5	2.9
% DK	0.0	2.6	2.2	0.0	13.3	12.5	6.1	5.6	0.0	3.5	0.0	29.9	12.3	6.2	2.1	0.0	5.8	6.0
N	394	383	224	406	810	32	279	410	414	1293	619	384	530	373	289	403	7243	

Appendix C: Item-by-Item Survey Results

Notes about item-by-item survey results:

- The tables contained in this Appendix are grouped by sub-domain (e.g., Community Inclusion).
- Each table displays data for **one** survey item.
- The title of each table contains the question number and wording as it appears on the NCI Consumer Survey.
- Results are listed **alphabetically** by state.
- The data presented are **unadjusted**, basic frequencies of responses.
- All valid response categories are broken out.
- For most items, “not applicable” and “no response” are considered “missing” data and therefore are not included in these tables.
- The “state average” represents the sum of all scores in the column divided by the number of states. This figure is preferred because it takes into account differences in sample sizes across states.
- The “total” line represents the results of the entire national sample (all states, all cases). This aggregate figure is **not adjusted for sample size**; therefore, some states may be under- or over-represented in the total.
- Only items that provided data for the indicators are listed. Probe questions and consistency checks are not included.
- **Q1 – Q24** are Section I questions, which **only allow consumer responses**.
- **Q28 – Q50** are Section II questions, which **allow other informants to respond** (except in the state of Vermont).
- Missing data is indicated as “Not available.”

COMMUNITY INCLUSION

Q28. Do you go shopping?

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>Total</i>
AL	8.8	91.2	374
CT	3.0	97.0	305
DE	13.4	86.6	224
HI	7.4	92.6	405
IN	5.6	94.4	802
KY	4.6	95.4	348
ME	4.4	95.6	295
NC	4.8	95.2	418
OK	1.7	98.3	414
PA	7.2	92.8	1251
RCOC	7.2	92.8	614
RI	6.8	93.2	381
SC	8.2	91.8	511
VT	5.2	94.8	153
WV	2.4	97.6	288
WY	0.7	99.3	401
State Average	5.7	94.3	
Total	5.9	94.1	7184

Q29. Do you go out on errands or appointments?

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>Total</i>
AL	2.7	97.3	372
CT	1.6	98.4	306
DE	9.8	90.2	224
HI	4.2	95.8	404
IN	1.9	98.1	801
KY	4.6	95.4	349
ME	0.3	99.7	293
NC	6.2	93.8	419
OK	1.0	99.0	414
PA	3.9	96.1	1211
RCOC	2.1	97.9	609
RI	4.2	95.8	379
SC	6.2	93.8	513
VT	5.2	94.8	153
WV	1.4	98.6	288
WY	0.5	99.5	401
State Average	3.5	96.5	
Total	3.3	96.7	7136

Q30. Do you go out for entertainment?

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>Total</i>
AL	7.5	92.5	372
CT	8.4	91.6	298
DE	26.9	73.1	223
HI	16.0	84.0	405
IN	9.0	91.0	798
KY	12.3	87.7	350
ME	10.3	89.7	291
NC	15.1	84.9	416
OK	3.4	96.6	414
PA	23.8	76.2	1275
RCOC	11.5	88.5	609
RI	12.5	87.5	376
SC	11.2	88.8	510
VT	28.6	71.4	154
WV	16.0	84.0	287
WY	2.0	98.0	401
State Average	13.4	86.6	
Total	13.6	86.4	7179

Q31. Do you always eat at home or do you sometimes go out to eat?

<i>State</i>	<i>% Always Eats At Home</i>	<i>% Sometimes Eats Out</i>	<i>Total</i>
AL	10.8	89.2	369
CT	7.3	92.7	300
DE	15.2	84.8	223
HI	6.9	93.1	406
IN	5.8	94.2	797
KY	6.6	93.4	348
ME	5.2	94.8	288
NC	6.9	93.1	419
OK	6.5	93.5	413
PA	6.6	93.4	1244
RCOC	8.8	91.2	611
RI	2.6	97.4	379
SC	7.4	92.6	499
VT	15.1	84.9	152
WV	3.1	96.9	287
WY	0.8	99.2	398
State Average	7.2	92.8	
Total	6.8	93.2	7133

Q32. Do you go to religious services?

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>Total</i>
AL	25.0	75.0	368
CT	52.4	47.6	294
DE	54.0	46.0	224
HI	59.2	40.8	397
IN	39.7	60.3	789
KY	43.1	56.9	348
ME	43.2	56.8	220
NC	31.8	68.2	409
OK	34.2	65.8	401
PA	39.1	60.9	1198
RCOC	45.8	54.2	607
RI	56.4	43.6	374
SC	30.0	70.0	500
VT	64.7	35.3	153
WV	41.8	58.2	285
WY	56.1	43.9	392
State Average	44.8	55.2	
Total	42.7	57.3	6959

Q33. Do you go to other meetings in the community?

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>Total</i>
AL	92.3	7.7	351
CT	76.0	24.0	292
DE	95.1	4.9	224
HI	94.3	5.7	402
IN	67.3	32.7	787
KY	85.6	14.4	348
ME	61.8	38.2	272
NC	87.8	12.2	409
OK	82.9	17.1	410
PA	35.3	64.7	1265
RCOC	79.1	20.9	602
RI	89.3	10.7	366
VT	67.8	32.2	146
WV	84.8	15.2	276
WY	94.0	6.0	400
State Average	79.6	20.4	
Total	73.2	26.8	6550

Q34. Do you exercise or play sports?

<i>State</i>	<i>% No</i>	<i>% Yes, In Non Integrated Settings</i>	<i>% Yes, In Community Settings</i>	<i>Total</i>
AL	38.9	37.0	24.1	365
CT	20.2	25.9	53.9	297
DE	42.8	16.7	40.5	222
HI	15.5	28.8	55.7	406
IN	21.3	19.3	59.4	798
KY	36.4	34.7	28.9	349
ME	18.6	29.9	51.5	291
NC	23.9	35.0	41.1	414
OK	40.4	37.0	22.5	413
PA	38.5	27.1	34.4	1262
RCOC	26.9	39.9	33.2	609
RI	13.9	48.1	38.0	374
SC	30.8	53.5	15.8	507
VT	21.6	0.0	78.4	153
WV	31.8	30.4	37.8	286
WY	7.0	28.3	64.8	400
State Average	26.8	30.7	42.5	
Total	27.8	31.7	40.5	7146

CHOICE AND DECISION-MAKING

Q35. Who chose the place where you live?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Person Had Some Input</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	85.0	11.7	3.3	274
CT	37.2	50.3	12.6	199
DE	48.2	48.2	3.6	139
HI	67.7	25.8	6.5	217
IN	28.0	53.1	18.9	471
KY	20.7	65.1	14.2	232
ME	52.2	37.7	10.1	247
NC	52.2	34.8	13.0	230
OK	48.4	36.4	15.2	382
PA	52.5	39.7	7.8	690
RCOC	46.8	31.6	21.6	329
RI	38.7	46.7	14.6	199
SC	22.1	53.5	24.3	226
VT	38.7	41.5	19.8	106
WV	51.0	35.4	13.5	96
WY	21.6	25.9	52.5	305
State Average	44.4	39.8	15.7	
Total	44.5	39.7	15.8	4342

Q36. How many places did you visit before moving here?

<i>State</i>	<i>% Did Not Visit</i>	<i>% Visited Only One</i>	<i>% Looked At More Than One</i>	<i>Total</i>
AL	54.5	18.3	27.2	224
CT	18.5	43.9	37.6	157
DE	28.2	41.9	29.8	124
HI	57.4	19.8	22.8	197
IN	6.5	38.7	54.8	416
KY	43.7	30.6	25.7	222
ME	27.2	46.6	26.2	191
NC	23.2	39.5	37.4	190
OK	36.9	33.7	29.4	279
PA	58.5	17.3	24.2	561
RCOC	25.6	27.6	46.7	246
RI	22.3	43.8	33.9	121
SC	18.5	75.2	6.3	222
WV	23.0	48.3	28.7	87
WY	9.0	34.9	56.1	301
State Average	30.2	37.3	32.5	
Total	31.9	34.5	33.6	3538

Q37. Did you choose the people you live with (or to live by yourself)?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Can Request A Change</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	89.7	5.9	4.4	272
CT	52.6	13.0	34.4	192
DE	20.5	62.8	16.7	156
HI	78.3	12.0	9.7	217
IN	31.4	24.8	43.7	455
KY	36.2	42.2	21.6	232
ME	64.2	12.5	23.3	232
NC	65.8	12.4	21.8	234
OK	57.4	22.0	20.7	387
PA	71.1	14.9	14.0	543
RCOC	68.0	7.7	24.3	338
RI	28.5	45.3	26.2	214
SC	41.8	2.3	55.9	220
VT	36.7	34.7	28.6	49
WV	57.9	9.5	32.6	95
WY	24.3	43.9	31.8	305
State Average	51.5	22.9	25.6	
Total	54.2	21.1	24.7	4141

Q38. Do you choose who helps you at home?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Can Request A Change</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	90.8	8.9	0.4	282
CT	33.5	35.6	30.9	233
DE	1.3	72.2	26.5	151
HI	76.5	17.8	5.6	213
IN	4.1	79.2	16.8	518
KY	8.4	74.9	16.7	263
ME	42.6	34.7	22.7	251
NC	37.5	48.0	14.5	304
OK	55.1	29.6	15.3	412
PA	76.6	16.2	7.2	704
RCOC	34.7	56.2	9.2	349
RI	22.7	55.5	21.8	238
SC	37.9	18.2	43.9	314
VT	32.4	24.3	43.2	37
WV	30.8	49.2	20.0	185
WY	2.5	87.1	10.3	319
State Average	36.7	44.2	19.1	
Total	39.8	43.9	16.3	4773

Q39. Who decides your daily schedule?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Person Had Some Input</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	57.1	23.7	19.1	371
CT	10.3	30.5	59.3	302
DE	29.9	59.8	10.3	224
HI	26.6	28.0	45.4	403
IN	13.4	28.6	58.0	791
KY	2.0	32.8	65.2	351
ME	16.7	37.6	45.7	282
NC	24.5	31.5	44.0	416
OK	26.4	32.9	40.7	413
PA	14.3	30.2	55.4	1250
RCOC	24.5	26.5	48.9	607
RI	7.3	28.8	63.9	368
SC	2.4	26.5	71.1	506
VT	8.2	18.5	73.3	146
WV	22.2	46.5	31.3	284
WY	5.0	18.7	76.3	401
State Average	18.2	31.3	50.5	
Total	17.6	30.3	52.2	7115

Q40. Who decides how you spend your free time?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Person Had Some Input</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	31.3	36.6	32.1	374
CT	3.0	22.6	74.3	296
DE	4.5	26.8	68.8	224
HI	26.1	23.6	50.2	402
IN	6.2	17.4	76.4	793
KY	0.6	26.3	73.1	350
ME	8.1	31.8	60.1	283
NC	6.9	26.5	66.6	419
OK	12.1	19.8	68.1	414
PA	4.7	21.4	74.0	1241
RCOC	9.4	20.5	70.1	605
RI	4.3	24.2	71.5	368
SC	3.7	22.4	73.8	508
VT	10.1	19.6	70.3	148
WV	11.1	33.4	55.4	287
WY	2.2	7.7	90.0	401
State Average	9.0	23.8	67.2	
Total	8.4	22.8	68.8	7113

Q41. Who chose the place where you work (or go during the day?)

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Person Had Some Input</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	92.7	7.0	0.3	342
CT	25.5	54.1	20.5	259
DE	47.3	47.3	5.4	184
HI	53.6	31.1	15.4	293
IN	23.9	51.9	24.2	599
KY	12.2	71.4	16.4	329
ME	42.0	43.3	14.7	238
NC	40.3	43.2	16.5	278
OK	36.9	47.7	15.4	325
PA	33.9	40.9	25.3	957
RCOC	51.4	33.1	15.5	477
RI	30.1	45.0	24.9	342
SC	14.8	52.1	33.1	399
VT	9.3	47.7	43.0	86
WV	49.8	34.4	15.8	215
WY	10.2	26.0	63.8	246
State Average	35.9	42.3	21.9	
Total	36.1	42.3	21.5	5569

Q42. How many places did you visit before working here?

<i>State</i>	<i>% Did Not Visit</i>	<i>% Visited Only One</i>	<i>% Looked At More Than One</i>	<i>Total</i>
AL	79.2	15.2	5.7	264
CT	15.1	43.9	41.0	205
DE	13.5	43.6	42.9	156
HI	41.9	28.5	29.7	246
IN	9.6	48.7	41.7	532
KY	39.6	29.2	31.1	318
ME	32.2	34.5	33.3	177
NC	24.6	35.9	39.5	248
OK	32.5	26.2	41.3	271
PA	68.2	11.2	20.5	988
RCOC	32.3	32.0	35.7	381
RI	17.8	43.9	38.2	157
SC	9.6	85.0	5.4	386
WV	23.3	50.3	26.4	193
WY	3.6	26.3	70.0	247
State Average	29.5	37.0	33.5	
Total	34.9	34.2	30.9	4769

Q43. Do you choose who helps you at work?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Can Request A Change</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	76.4	21.9	1.7	347
CT	35.3	37.3	27.4	252
DE	0.5	99.1	0.5	215
HI	44.7	47.4	7.8	293
IN	3.4	88.2	8.4	584
KY	6.6	79.0	14.4	334
ME	36.8	41.3	22.0	223
NC	30.4	62.3	7.3	260
OK	66.3	21.0	12.7	315
PA	67.3	18.5	14.2	896
RCOC	29.8	62.1	8.1	467
RI	40.4	44.3	15.4	332
SC	18.8	38.9	42.3	452
VT	28.8	21.2	50.0	52
WV	30.5	60.4	9.1	197
WY	0.4	82.3	17.2	232
State Average	32.3	51.6	16.2	
Total	35.5	49.9	14.6	5451

Q 44. Do you choose what to buy with your spending money?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Person Had Some Input</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	33.6	42.4	24.0	375
CT	4.1	30.0	65.9	293
DE	20.2	68.6	11.2	223
HI	24.8	40.0	35.2	403
IN	7.7	30.3	62.0	789
KY	1.7	32.2	66.1	351
ME	10.1	34.4	55.6	288
NC	11.3	37.3	51.4	416
OK	11.4	30.7	58.0	414
PA	7.8	21.4	70.8	1245
RCOC	11.9	22.7	65.4	607
RI	10.9	44.4	44.7	367
SC	4.4	36.2	59.4	503
VT	2.1	32.9	65.1	146
WV	18.8	41.5	39.7	287
WY	4.3	11.5	84.2	399
State Average	11.6	34.8	53.7	
Total	10.9	31.7	57.3	7106

Q45. Did you choose your case manager/service coordinator?

<i>State</i>	<i>% Someone Else Chose</i>	<i>% Can Request A Change</i>	<i>% Person Chose Without Help</i>	<i>Total</i>
AL	79.1	20.1	0.8	368
CT	64.4	29.5	6.0	281
DE	98.6	0.9	0.5	221
HI	37.2	60.6	2.3	393
IN	17.6	37.4	45.0	714
KY	18.4	72.8	8.8	342
ME	61.8	27.6	10.6	254
NC	39.2	55.6	5.2	383
OK	75.3	18.6	6.0	397
PA	92.4	4.2	3.4	1153
RCOC	24.1	72.9	3.1	590
RI	62.2	28.0	9.7	339
SC	5.6	82.3	12.1	464
VT	42.3	27.0	30.7	137
WV	37.0	57.9	5.1	273
WY	16.5	21.9	61.6	388
State Average	48.2	38.6	13.2	
Total	49.2	37.4	13.3	6697

RELATIONSHIPS

Q11. Do you have friends you like to talk or do things with?

State	% No	% Yes - Staff Or Family	% Yes - Not Staff Or Family	Total
AL	8.5	21.1	70.4	199
CT	7.7	12.7	79.6	260
DE	3.8	32.1	64.1	131
HI	5.7	27.6	66.7	228
IN	4.4	17.9	77.7	642
KY	2.8	14.5	82.6	317
ME	9.6	0.0	90.4	187
NC	11.0	24.7	64.4	292
OK	4.9	2.5	92.6	204
PA	11.5	26.1	62.4	970
RCOC	13.0	7.0	80.0	454
RI	4.3	14.1	81.5	276
SC	21.1	63.3	15.6	360
VT	7.3	19.2	73.5	151
WV	10.6	21.2	68.2	151
WY	6.7	7.8	85.5	269
State Average	8.3	19.5	72.2	
Total	9.0	20.7	70.4	5091

Q10. Do you have a best friend or someone you are really close to?

State	% No	% Yes	Total
AL	16.9	83.1	201
CT	10.2	89.8	255
DE	23.6	76.4	123
HI	7.4	92.6	215
IN	11.6	88.4	612
KY	6.3	93.7	316
ME	5.1	94.9	178
NC	18.8	81.2	292
OK	10.7	89.3	206
PA	14.5	85.5	938
RCOC	22.1	77.9	456
RI	21.5	78.5	270
SC	21.9	78.1	356
VT	13.1	86.9	153
WV	20.5	79.5	151
WY	8.2	91.8	269
State Average	14.5	85.5	
Total	14.6	85.4	4991

Q12. Can you see your friends when you want to see them?

<i>State</i>	<i>% No</i>	<i>% Sometimes</i>	<i>% Yes</i>	<i>Total</i>
AL	6.9	32.9	60.1	173
CT	3.4	12.9	83.6	232
DE	14.9	57.9	27.3	121
HI	10.0	21.0	69.0	210
IN	3.4	9.9	86.6	583
KY	3.0	7.9	89.1	303
ME	2.2	13.8	84.0	181
NC	6.1	16.3	77.6	246
OK	1.0	6.2	92.7	193
PA	2.8	9.5	87.7	821
RCOC	5.7	21.0	73.3	386
RI	3.6	6.9	89.5	247
SC	3.5	6.0	90.5	284
VT	4.3	7.2	88.5	139
WV	6.2	11.6	82.2	129
WY	0.4	2.8	96.8	250
State Average	4.8	15.2	79.9	
Total	4.2	13.0	82.8	4498

Q14. Can you see your family when you want to?

<i>State</i>	<i>% No</i>	<i>% Sometimes</i>	<i>% Yes</i>	<i>Total</i>
AL	5.3	32.1	62.6	190
CT	5.6	18.4	76.0	250
DE	10.0	31.7	58.3	120
HI	3.5	22.6	73.9	199
IN	4.6	14.1	81.3	604
KY	5.4	8.4	86.1	296
ME	4.5	25.8	69.7	198
NC	4.3	16.3	79.3	276
OK	11.7	22.2	66.1	180
PA	3.4	3.6	93.1	475
RCOC	7.8	22.5	69.6	408
RI	2.8	2.8	94.4	249
SC	4.2	14.1	81.7	333
VT	7.2	8.8	84.0	125
WV	7.0	10.5	82.5	143
WY	8.7	6.8	84.4	263
State Average	6.0	16.3	77.7	
Total	5.6	14.9	79.5	4309

Q13. Do you ever feel lonely?

State	% Never	% Sometimes	% Often	Total
AL	53.1	34.2	12.8	196
CT	56.7	29.9	13.4	254
DE	47.9	43.8	8.3	121
HI	57.8	34.4	7.8	218
IN	56.0	34.1	9.9	596
KY	39.7	49.8	10.5	315
ME	51.0	38.9	10.1	198
NC	48.4	37.6	13.9	287
OK	45.4	39.8	14.8	196
PA	56.5	38.2	5.2	939
RCOC	54.5	32.1	13.4	448
RI	58.2	30.8	11.0	273
SC	47.1	31.0	21.9	329
VT	60.6	29.6	9.9	142
WV	59.7	30.9	9.4	149
WY	73.6	22.3	4.2	265
State Average	54.1	34.8	11.0	
Total	54.4	35.1	10.5	4926

SATISFACTION

Q1. Do you like working at [your job or day activity]?

<i>State</i>	<i>% No</i>	<i>% In-Between</i>	<i>% Yes</i>	<i>Total</i>
AL	6.7	4.3	88.9	208
CT	3.2	5.6	91.1	248
DE	3.1	17.8	79.1	129
HI	2.4	4.8	92.9	168
IN	2.6	5.0	92.4	540
KY	2.3	2.3	95.3	299
ME	6.6	8.2	85.2	182
NC	6.3	5.4	88.3	222
OK	1.7	5.0	93.3	179
PA	4.9	5.4	89.8	803
RCOC	7.6	8.1	84.4	397
RI	4.7	5.8	89.5	275
SC	5.6	2.2	92.3	323
VT	0.8	2.5	96.7	120
WV	4.8	2.4	92.9	126
WY	0.5	1.0	98.5	202
State Average	4.0	5.4	90.7	
Total	4.3	5.2	90.5	4421

Q3. Do you like your home or where you live?

<i>State</i>	<i>% No</i>	<i>% In-Between</i>	<i>% Yes</i>	<i>N</i>
AL	7.1	2.4	90.6	212
CT	4.5	7.9	87.6	266
DE	3.0	12.8	84.2	133
HI	3.5	2.7	93.8	226
IN	3.8	7.0	89.1	654
KY	3.2	2.2	94.6	316
ME	7.2	10.1	82.7	208
NC	6.4	7.4	86.2	298
OK	3.8	7.7	88.5	208
PA	5.2	5.6	89.3	1008
RCOC	4.1	6.7	89.2	462
RI	6.5	3.1	90.4	291
SC	20.5	2.8	76.7	361
VT	3.7	5.3	90.9	187
WV	7.1	3.2	89.7	155
WY	7.4	3.0	89.6	270
State Average	6.1	5.6	88.3	
Total	6.1	5.5	88.4	5255

Q. 21 Are you happy with your personal life, or do you feel unhappy?

State	% Unhappy	% In Between	% Happy	Valid N
AL	3.8	17.1	79.1	211
CT	2.2	14.2	83.5	267
DE	3.1	32.8	64.1	131
KY	4.5	7.3	88.2	314
NC	3.1	23.8	73.1	294
OK	4.0	17.3	78.7	202
PA	5.1	21.5	73.4	990
RCOC	4.0	17.8	78.2	455
RI	2.8	16.0	81.1	281
SC	6.2	9.1	84.7	274
WV	3.9	11.8	84.3	153
WY	4.8	5.9	89.3	270
State Average	3.9	16.2	79.8	
Total	4.2	16.7	79.1	3842

SERVICE COORDINATION

Q17. If you ask for something, does [your case manager/service coordinator] help you get what you need?

<i>State</i>	% No	% Sometimes	% Yes	Total
AL	5.1	19.7	75.2	137
CT	5.5	11.1	83.4	199
DE	2.6	27.6	69.7	76
HI	5.5	14.5	80.0	165
IN	1.6	6.9	91.5	494
KY	2.0	4.3	93.7	301
ME	6.5	11.8	81.7	153
NC	4.3	13.8	81.8	253
OK	2.2	14.0	83.9	186
PA	9.4	13.7	76.9	776
RCOC	5.0	11.1	83.8	359
RI	2.5	5.0	92.5	240
SC	0.0	14.9	85.1	295
VT	3.8	4.6	91.6	131
WV	6.7	14.2	79.1	134
WY	2.7	1.5	95.8	260
State Average	4.1	11.8	84.1	
Total	4.5	10.8	84.7	4159

Q15. Do you know your case manager/service coordinator?

<i>State</i>	% No	% Maybe	% Yes	Total
AL	31.0	6.6	62.4	197
CT	17.4	9.5	73.1	264
DE	34.4	3.3	62.3	122
HI	24.4	8.4	67.1	225
IN	15.7	7.1	77.2	604
KY	2.9	2.2	94.9	313
ME	18.6	9.0	72.3	188
NC	6.9	3.2	89.9	277
OK	3.9	1.0	95.1	204
PA	14.4	0.0	85.6	928
RCOC	13.2	6.7	80.1	448
RI	7.9	2.5	89.6	278
SC	6.7	12.5	80.8	328
VT	5.5	6.2	88.4	146
WV	7.9	7.3	84.8	151
WY	2.3	0.4	97.4	266
State Average	13.3	5.4	81.3	
Total	12.8	4.8	82.4	4939

Q16. Does [your case manager/service coordinator] ask you what you want?

State	% No	% Sometimes	% Yes	Total
AL	3.7	10.4	85.9	135
CT	6.4	16.7	76.8	203
DE	2.5	37.5	60.0	80
HI	8.6	11.7	79.8	163
IN	5.6	9.0	85.4	479
KY	1.3	4.6	94.0	302
ME	3.4	6.0	90.6	149
NC	8.6	12.1	79.3	256
OK	4.8	22.0	73.1	186
PA	12.3	14.8	72.9	786
RCOC	11.9	11.6	76.5	371
RI	4.9	6.9	88.2	245
SC	4.6	14.8	80.6	283
VT	14.7	6.2	79.1	129
WV	4.7	19.4	76.0	129
WY	1.5	1.9	96.5	260
State Average	6.2	12.9	80.9	
Total	7.1	11.8	81.1	4156

ACCESS

Q19. Do people help you do new things you want to do?

<i>State</i>	% No	% Sometimes	% Yes	Total
AL	7.6	9.6	82.7	197
CT	8.3	19.0	72.7	253
DE	4.8	13.6	81.6	125
HI	4.6	27.2	68.2	217
IN	1.7	20.4	77.9	587
KY	15.4	0.0	84.6	123
ME	2.5	15.6	81.9	199
NC	7.1	9.6	83.3	282
OK	6.5	15.5	78.0	200
PA	34.2	0.0	65.8	263
RCOC	15.2	8.2	76.6	440
RI	14.1	7.8	78.1	269
SC	4.5	2.5	93.0	359
VT	13.3	6.7	80.0	150
WV	5.3	18.7	76.0	150
WY	1.5	0.7	97.8	269
State Average	9.2	10.9	79.9	
Total	8.9	11.2	79.9	4083

Q20. Do you want [more] help to do or learn new things?

<i>State</i>	% No	% Yes	Total
AL	18.5	81.5	81
CT	27.6	72.4	192
DE	19.0	81.0	21
KY	11.9	88.1	160
NC	28.4	71.6	95
OK	13.6	86.4	59
PA	30.2	69.8	765
RCOC	30.4	69.6	171
RI	34.9	65.1	63
SC	3.5	96.5	256
VT	34.7	65.3	101
WV	31.2	68.8	77
WY	50.0	50.0	6
State Average	25.7	74.3	2047
Total	24.5	75.5	

Q22. When you want to go somewhere, do you always have a way to get there?

<i>State</i>	<i>% Almost Never</i>	<i>% Sometimes</i>	<i>% Almost Always</i>	<i>Total</i>
AL	6.3	41.0	52.7	205
CT	0.8	10.6	88.6	264
DE	10.5	62.1	27.4	124
HI	0.4	4.4	95.2	227
IN	1.2	13.9	84.9	649
KY	1.6	21.7	76.7	313
ME	1.5	12.2	86.3	205
NC	3.5	19.7	76.8	289
OK	5.4	8.3	86.3	205
PA	2.9	12.1	84.9	990
RCOC	3.4	15.9	80.8	447
RI	1.8	12.5	85.6	271
SC	5.8	3.9	90.3	360
VT	2.6	6.5	90.8	153
WV	0.0	13.9	86.1	151
WY	2.2	3.3	94.4	269
State Average	3.1	16.4	80.5	
Total	2.9	14.3	82.8	5122

Q50. Do you get the services you need?

<i>State</i>	<i>% No</i>	<i>% Sometimes</i>	<i>% Yes</i>	<i>Total</i>
AL	2.1	6.1	91.7	375
CT	2.8	11.1	86.2	289
DE	2.7	36.8	60.5	223
HI	7.4	6.7	85.9	390
IN	4.8	19.9	75.3	789
KY	3.5	4.1	92.4	342
ME	2.8	5.7	91.5	282
NC	7.3	14.8	77.9	412
OK	9.4	1.7	88.9	413
PA	10.5	7.1	82.4	952
RCOC	4.8	16.3	78.8	600
RI	30.2	3.5	66.3	374
SC	5.4	4.8	89.7	497
VT	7.5	2.1	90.4	146
WV	18.2	23.8	58.0	286
WY	1.7	2.2	96.0	401
State Average	7.6	10.4	82.0	
Total	7.6	10.4	82.0	6771

SAFETY

Q5. Are you ever afraid or scared when you are at home?

<i>State</i>	% Rarely	% Sometimes	% Most Of The Time	Total
AL	83.9	14.1	2.0	205
CT	85.9	10.2	3.9	256
DE	73.6	26.4	0.0	129
HI	88.8	8.0	3.1	224
IN	87.9	9.4	2.7	629
KY	79.8	15.7	4.5	312
ME	74.2	21.7	4.0	198
NC	84.8	11.4	3.8	290
OK	82.5	11.7	5.8	206
PA	82.5	15.0	2.5	974
RCOC	82.4	15.2	2.4	454
RI	90.0	8.0	2.1	289
SC	72.8	10.9	16.3	331
VT	97.4	0.6	1.9	154
WV	80.1	16.0	3.8	156
WY	98.1	0.7	1.1	269
State Average	84.0	12.2	3.7	
Total	84.1	12.2	3.7	5076

Q6. Are you ever afraid or scared when you are out in your neighborhood?

<i>State</i>	% Rarely	% Sometimes	% Most Of The Time	Total
AL	81.1	14.4	4.5	201
CT	81.7	10.3	7.9	252
DE	84.9	15.1	0.0	126
HI	84.2	13.1	2.7	222
IN	85.1	10.1	4.8	624
KY	80.9	14.6	4.5	309
ME	80.8	17.2	2.0	198
NC	81.1	12.6	6.3	286
OK	79.6	14.1	6.3	206
PA	83.7	13.3	3.0	946
RCOC	77.2	17.2	5.6	448
RI	91.8	6.8	1.4	281
SC	70.7	8.5	20.7	328
VT	94.4	3.5	2.1	142
WV	81.9	12.9	5.2	155
WY	98.5	0.7	0.7	269
State Average	83.6	11.5	4.9	
Total	83.2	11.8	5.0	4993

HEALTH AND WELL-BEING

BI-19. When was his/her last physical exam?

<i>State</i>	% Within Past Year	% Over A Year Ago	% Don't Know	Total
AL	88.8	5.9	5.4	392
CT	86.7	3.4	9.9	413
DE	75.3	5.4	19.3	223
HI	58.9	28.8	12.3	406
IN	96.3	2.3	1.4	810
KY	94.8	3.6	1.6	503
ME	95.5	1.7	2.7	292
NC	88.3	6.9	4.8	461
OK	97.8	1.7	0.5	414
PA	84.7	4.5	10.8	1339
RCOC	58.2	24.7	17.1	619
RI	80.9	9.1	9.9	383
SC	73.6	15.5	10.9	530
VT	78.3	10.2	11.5	373
WV	97.6	0.3	2.1	289
WY	87.3	0.0	12.7	403
State Average	83.9	7.8	8.3	
Total	83.8	7.8	8.3	7850

BI-20. If female, when was her last OB/GYN exam?

<i>State</i>	% Within Past Year	% Over A Year Ago	% Never Had An Exam	% Don't Know	Total
AL	67.7	9.8	0.6	22.0	164
CT	64.3	14.8	3.6	17.3	196
DE	60.0	10.0	2.2	27.8	90
HI	31.7	24.6	1.0	42.7	199
IN	64.1	7.2	13.8	14.9	348
KY	78.1	13.7	1.8	6.4	219
ME	51.2	18.1	8.7	22.0	127
NC	67.7	11.6	3.7	16.9	189
OK	66.0	19.0	7.8	7.2	153
PA	49.7	11.5	5.0	33.8	600
RCOC	24.7	18.5	7.4	49.4	271
RI	51.5	9.4	7.6	31.6	171
SC	46.2	31.2	7.7	14.9	221
WV	39.4	20.5	33.3	6.8	132
WY	75.3	8.4	5.3	11.1	190
State Average	55.8	15.2	7.3	21.7	
Total	54.8	14.6	7.0	23.6	3270

BI-21. When was his/her last dentist visit?

<i>State</i>	% Within Last Six Months	% Over Six Months Ago	% Don't Know	Total
AL	44.4	42.1	13.6	390
CT	66.7	19.0	14.2	415
DE	59.8	11.6	28.6	224
HI	15.3	60.8	23.9	406
IN	67.1	26.7	6.2	809
KY	54.9	37.3	7.8	488
ME	62.2	30.2	7.6	278
NC	53.6	35.9	10.5	459
OK	56.5	35.0	8.5	414
PA	45.6	26.1	28.2	1335
RCOC	27.9	48.6	23.4	619
RI	49.0	19.8	31.3	384
SC	39.2	39.1	21.7	530
VT	54.7	20.1	25.2	373
WV	66.1	29.1	4.8	289
WY	75.7	11.7	12.7	403
State Average	52.4	30.8	16.8	
Total	51.0	31.3	17.7	7816

BI-22. Is weight a concern for this person?

<i>State</i>	% Underweight	% Overweight	% No	% Don't Know	Total
AL	10.4	34.2	54.4	1.0	395
CT	5.8	27.2	64.3	2.7	412
DE	6.3	21.0	67.0	5.8	224
KY	7.0	20.7	71.3	1.0	502
NC	2.9	27.5	67.6	2.0	447
OK	8.0	28.5	63.5	0.0	414
PA	3.3	26.8	61.1	8.8	1341
RCOC	2.9	24.2	72.7	0.2	619
RI	5.7	29.2	62.1	2.9	383
SC	2.2	23.8	62.2	11.9	185
VT	4.0	25.5	66.2	4.3	373
WV	9.3	32.5	57.8	0.3	289
WY	5.0	28.0	54.3	12.7	403
State Average	5.6	26.9	63.4	4.1	
Total	5.2	26.8	63.6	4.4	5987

BI-23. Does this person smoke or chew tobacco?

<i>State</i>	% No	% Yes	% Don't Know	% Total
AL	79.7	9.4	10.9	395
CT	93.5	5.3	1.2	414
DE	90.6	4.9	4.5	223
KY	85.9	11.7	2.4	496
NC	83.0	16.6	0.4	453
OK	89.1	10.4	0.5	414
PA	81.9	9.4	8.7	1344
RCOC	95.8	2.6	1.6	619
RI	90.9	7.3	1.8	384
SC	77.3	7.6	15.1	185
VT	84.7	12.3	2.9	373
WV	90.6	9.4	0.0	286
WY	78.7	8.7	12.7	403
State Average	86.3	8.9	4.8	
Total	86.0	9.0	5.0	5989

BI-24. How physically active is this person?

<i>State</i>	% Very Active	% Moderately Active	% Physically Inactive	% Don't Know	Total
AL	26.6	43.9	18.3	11.3	399
CT	13.0	62.7	21.0	3.4	415
DE	14.7	47.3	31.7	6.3	224
KY	18.5	48.5	29.4	3.6	497
NC	12.9	58.7	27.5	0.9	443
OK	30.9	48.6	20.5	0.0	414
PA	11.3	56.5	23.0	9.2	1342
RCOC	35.1	52.0	12.9	0.0	619
RI	12.0	63.5	21.1	3.4	384
SC	13.0	56.8	17.8	12.4	185
VT	16.4	63.3	18.2	2.1	373
WV	20.4	52.9	26.6	0.0	289
WY	24.6	39.2	23.6	12.7	403
State Average	19.2	53.4	22.4	5.0	
Total	18.8	53.8	22.1	5.2	5987

MEDICATIONS

BI-16. Does this person currently take medications for...?

Mood disorders

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>% Don't' Know</i>	<i>Total</i>
AL	65.7	32.3	2.0	399
CT	62.3	33.4	4.3	395
DE	65.2	22.8	12.1	224
HI	81.0	17.7	1.2	406
IN	62.7	33.5	3.8	810
KY	55.4	44.6		509
OK	63.3	36.2	0.5	414
PA	60.7	32.3	7.0	1309
RCOC	77.4	22.6		619
RI	62.1	30.3	7.6	383
SC	69.1	23.6	7.4	530
WV	61.2	37.7	1.0	289
WY	64.7	35.3		402
State Average	65.4	31.0	4.7	
Total	65.0	31.2	3.8	6689

Anxiety

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>% Don't' Know</i>	<i>Total</i>
AL	72.2	25.3	2.5	399
CT	65.5	30.2	4.3	397
DE	67.0	21.0	12.1	224
HI	81.0	17.7	1.2	406
IN	71.1	24.4	4.4	810
KY	61.9	38.1		509
OK	71.7	27.8	0.5	414
PA	71.9	20.8	7.3	1297
RCOC	84.5	15.5		619
RI	64.8	27.3	7.8	384
SC	80.4	12.3	7.4	530
WV	71.6	27.0	1.4	289
WY	79.7	20.3		403
State Average	72.6	23.7	4.9	
Total	72.9	23.1	4.0	6681

Behavior problems

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>% Don't' Know</i>	<i>Total</i>
AL	65.1	33.7	1.3	398
CT	67.8	29.0	3.3	400
DE	67.9	25.0	7.1	224
HI	79.3	19.5	1.2	406
IN	69.5	26.5	4.0	810
KY	67.4	32.6		509
OK	72.0	27.5	0.5	414

PA	75.9	18.0	6.1	1303
RCOC	85.1	14.9		619
RI	72.9	19.8	7.3	384
SC	71.5	23.6	4.9	530
WV	67.5	31.5	1.0	289
WY	78.4	21.6		402
State Average	72.3	24.9	3.7	
Total	73.2	23.7	3.1	6688

Psychotic disorder

<i>State</i>	<i>% No</i>	<i>% Yes</i>	<i>% Don't' Know</i>	<i>Total</i>
AL	76.6	21.2	2.3	397
CT	74.4	21.6	4.0	398
DE	75.0	12.9	12.1	224
KY	84.3	15.7		509
OK	84.8	15.0	0.2	414
PA	79.1	12.2	8.7	1290
RCOC	83.7	16.3		619
RI	82.2	10.2	7.6	383
SC	81.6	10.3	8.1	185
WV	86.2	11.4	2.4	289
WY	81.1	18.9		402
State Average	80.8	15.1	5.7	
Total	80.8	15.0	4.2	5110

RESPECT AND RIGHTS

Q18. Do you know who your advocate or guardian is?

State	% No	% Maybe, not sure	% Yes	Total
AL	43.6	5.3	51.1	94
CT	5.7	3.1	91.2	159
DE	6.3	13.7	80.0	95
HI	3.5	3.5	92.9	141
IN	5.6	3.9	90.5	304
KY	4.0	8.5	87.5	176
ME	6.3	4.2	89.5	143
NC	7.6	4.9	87.5	224
OK	1.8	0.6	97.6	165
RCOC	29.1	12.0	58.9	275
RI	3.5	2.2	94.3	229
SC	12.2	1.4	86.4	294
VT	3.9	6.5	89.6	77
WV	13.1	3.7	83.2	107
WY	0.5	2.6	96.9	191
State Average	9.8	5.1	85.1	
Total	9.6	4.8	85.6	2674

Q46. Do people read your mail without your permission?

State	% No	% Some Mail	% Yes	Total
AL	97.0	0.5	2.5	197
CT	89.3	0.4	10.4	280
DE	73.0	0.0	27.0	204
HI	72.0	6.0	22.0	332
IN	91.9	3.8	4.2	732
KY	90.1	2.6	7.3	344
ME	76.6	13.0	10.4	269
NC	88.7	0.0	11.3	364
OK	85.8	0.0	14.2	401
PA	79.2	0.0	20.8	1141
RCOC	94.8	0.0	5.2	534
RI	98.9	0.0	1.1	358
SC	53.6	1.1	45.3	444
VT	87.7	0.0	12.3	130
WV	57.4	14.8	27.8	263
WY	96.8	0.0	3.2	380
State Average	83.3	2.6	14.1	
Total	83.5	2.2	14.4	6373

Q47. Can you be alone with [guests], or does someone have to be with you?

State	% Someone Always Present	% Some Restrictions	% Can Be Alone With Guests	Total
AL	19.0	0.0	81.0	158
CT	10.5	0.4	89.0	228
DE	4.0	0.0	96.0	149
HI	21.8	4.9	73.2	142
IN	10.3	8.6	81.1	572
KY	5.2	2.5	92.3	326
ME	10.6	16.9	72.5	236
NC	11.9	0.0	88.1	278
OK	10.6	0.0	89.4	398
PA	11.0	0.0	89.0	1208
RCOC	12.6	0.0	87.4	373
RI	12.2	0.0	87.8	270
SC	11.8	30.4	57.8	391
VT	19.6	0.0	80.4	107
WV	11.9	22.7	65.4	185
WY	12.1	0.0	87.9	387
State Average	12.2	5.4	82.4	
Total	11.4	4.9	83.7	5408

Q48. Are you allowed to use the phone when you want to?

State	% Not Allowed	% Some Restrictions	% Can Use Anytime	Total
AL	9.0	0.4	90.6	234
CT	7.0	0.4	92.6	270
DE	9.8	0.0	90.2	173
HI	3.3	11.2	85.5	214
IN	1.2	6.1	92.7	675
KY	7.5	2.5	90.0	321
ME	1.2	13.1	85.7	245
NC	11.5	0.0	88.5	323
OK	3.5	0.0	96.5	368
PA	10.2	0.0	89.8	1064
RCOC	9.4	0.0	90.6	458
RI	5.2	0.0	94.8	305
SC	14.5	4.9	80.6	470
VT	8.2	0.0	91.8	147
WV	4.1	17.9	77.9	195
WY	4.6	0.0	95.4	393
State Average	6.9	3.5	89.6	
Total	7.2	2.8	90.0	5855

Q8. Do people (including staff) let you know before they come into your home?

State	% No	% Sometimes	% Yes	Total
AL	2.9	6.8	90.3	206
CT	7.0	6.6	86.4	258
DE	6.3	11.7	82.0	128
HI	1.4	3.6	95.0	220
IN	2.3	4.4	93.4	619
KY	4.4	1.6	94.0	316
ME	10.1	12.6	77.3	198
NC	8.3	7.6	84.1	290
OK	3.4	15.0	81.6	207
PA	5.2	6.0	88.8	943
RCOC	2.7	6.6	90.7	440
RI	1.4	1.4	97.2	282
SC	22.0	2.4	75.6	336
VT	5.7	5.7	88.7	141
WV	3.9	9.1	87.0	154
WY	3.7	2.2	94.1	269
State Average	5.7	6.5	87.9	
Total	5.5	5.8	88.7	5007

Q9. Do people (including staff) ask permission before coming into your bedroom?

State	% No	% Sometimes	% Yes	Total
AL	7.5	12.4	80.1	201
CT	7.0	9.7	83.3	257
DE	20.5	40.2	39.3	112
HI	17.6	11.3	71.2	222
IN	3.8	6.6	89.7	610
KY	6.7	2.2	91.1	314
ME	9.5	9.0	81.5	200
NC	8.9	9.2	81.8	292
OK	2.9	8.3	88.8	205
PA	10.9	9.3	79.8	777
RCOC	9.3	8.9	81.8	440
RI	2.5	2.5	95.1	285
SC	21.4	3.3	75.3	336
VT	13.0	5.1	81.9	138
WV	10.0	15.3	74.7	150
WY	5.6	1.9	92.6	270
State Average	9.8	9.7	80.5	
Total	9.2	8.2	82.6	4809

Q49. Have you ever participated in a self-advocacy group, meeting, conference, or event?

State	% No	% Had Opportunity But Chose Not To	% Yes	Total
AL	85.7	0.4	13.9	230
CT	61.1	7.8	31.1	257
DE	56.3	16.4	27.2	213
HI	55.6	22.2	22.2	27
IN	60.7	5.4	33.9	682
KY	55.3	2.6	42.1	304
ME	47.4	10.7	41.9	253
NC	68.3	2.9	28.8	375
OK	58.0	4.1	37.9	364
PA	83.1	8.9	8.0	1051
RCOC	73.2	1.6	25.1	553
RI	71.1	6.9	22.0	350
SC	69.6	0.4	30.0	464
VT	46.2	18.9	35.0	143
WV	81.8	2.9	15.3	137
WY	72.4	0.8	26.8	399
State Average	65.4	7.1	27.6	
Total	68.5	5.6	25.9	5802

Q4. Can you be alone if you want to?

State	% No	% Yes	Total
AL	18.8	81.2	197
CT	5.1	94.9	234
DE	4.2	95.8	118
HI	9.5	90.5	210
IN	4.7	95.3	577
KY	6.1	93.9	297
ME	8.4	91.6	191
NC	12.7	87.3	252
OK	5.9	94.1	205
PA	4.5	95.5	912
RCOC	10.6	89.4	369
RI	7.9	92.1	242
SC	5.2	94.8	328
VT	15.1	84.9	146
WV	4.0	96.0	150
WY	9.7	90.3	258
State Average	8.3	91.7	
Total	7.4	92.6	4686

Q2. Is [staff who helps you at job/day activity] nice and polite to you?

State	% No	% Some Staff	% Yes	Total
AL	1.9	3.4	94.7	207
CT	0.4	1.7	97.8	230
DE	0.8	8.1	91.1	123
HI	0.0	16.9	83.1	166
IN	0.4	4.4	95.2	540
KY	0.7	5.0	94.3	300
ME	1.2	5.5	93.3	165
NC	1.9	6.6	91.5	211
OK	0.6	4.1	95.3	172
PA	2.0	8.5	89.5	656
RCOC	2.2	5.3	92.5	361
RI	0.4	2.7	97.0	263
SC	3.0	11.1	85.9	333
VT	2.1	1.0	96.9	97
WV	2.6	0.9	96.6	116
WY	0.5	1.6	97.9	192
State Average	1.3	5.4	93.3	
Total	1.3	5.9	92.8	4132

Q7. Is [staff who helps you at home] nice and polite to you?

State	% No	% Some Staff	% Yes	Total
AL	7.8	6.5	85.6	153
CT	2.3	8.1	89.6	221
DE	0.0	6.7	93.3	75
HI	3.8	7.7	88.5	104
IN	3.6	5.5	91.0	421
KY	5.7	2.9	91.4	245
ME	2.1	5.6	92.3	195
NC	3.7	5.0	91.3	218
OK	1.5	4.4	94.2	206
PA	1.2	7.6	91.2	498
RCOC	13.1	5.4	81.4	312
RI	3.3	3.3	93.4	181
SC	20.4	10.9	68.7	265
VT	1.6	9.5	88.9	63
WV	6.3	1.8	92.0	112
WY	1.3	1.7	96.9	229
State Average	4.9	5.8	89.4	
Total	5.2	5.8	88.9	3498

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Appendix D: Comparability of Questions Across Past Versions

NCI Consumer Survey -- Comparability of Questions Across Past Versions

Codes:

O.K. for longitudinal analysis
questionable, may have comparability problems
not comparable, do not use

Question/Number	Phase VII FY05 data	Phase V- VI FY03 and FY04 data V.2002	Phase IV FY02 data V.2001	Phase III FY01 data V.2000	Phase II FY00 data V.2 (1999)	Comments
taking meds for mood, anxiety, or behavior (*added psychotic disorders in Phase VII)	BI-16	BI-17	BI-17	BI-17	BI-19	DK code changed from 9 to 3 in 2001. In 1999, all three in one category.
had physical exam in past year	BI-19	BI-20	BI-20	BI-20	BI-22	"n/a in records" added to DK response in 2001
had GYN exam in past year	BI-20	BI-21	BI-21	BI-21	BI-23	"n/a in records" added to DK response in 2001
had routine dental exam in past 6 months	BI-21	BI-22	BI-22	BI-22	BI-24	"n/a in records" added to DK response in 2001
Is weight a concern?	BI-22					
Does person smoke or chew tobacco?	BI-23					
How physically active is person?	BI-24					
type of residence	BI-25	BI-24	BI-24	BI-24	BI-26	Demographic
who owns or leases residence	BI-27	BI-25	BI-25	BI-25	BI-27	Demographic
receives HCBS funding	BI-30	BI-29	BI-29	BI-29	BI-31	Demographic
Currently uses self-directed supports option?	BI-31					
has individually-negotiated budget	BI-32	BI-30	BI-30	BI-30	n/a	
has person-centered plan	BI-33	BI-30	BI-30	BI-30	n/a	
uses FI or ISO	BI-34	BI-30	BI-30	BI-30	n/a	
microboard manages funds	BI-35	BI-30	BI-30	BI-30	n/a	
has support broker or personal agent	BI-36	BI-30	BI-30	BI-30	n/a	

Question/Number	Phase VII	Phase V- VI	Phase IV	Phase III	Phase II	Comments
	FY05 data	FY03 and FY04 data	FY02 data	FY01 data	FY00 data	
	V.2002	V.2001	V.2000	V.2 (1999)		
satisfied with job or day program	1	1	1	1	1&6	day and work separated in 1999
day staff nice (treat with respect)	2	2	2	2	4&8	day and work separated in 1999
<i>consistency check</i>		3	3	8		Dropped
satisfied with home	3	4	4	13	19	
can be alone, have privacy	4	5	5	14	21	Wording of question changed y/n codes reversed in V.2000 - should not affect outcome but may have caused data entry errors. 1999 wording different y/n codes reversed in V.2000 - should not affect outcome but may have caused data entry errors. 1999 wording different slightly re-phrasing of question; probably O.K.
afraid at home	5	6	6	15	22	
afraid in neighborhood	6	7	7	16	22	
home staff nice (treat with respect)	7	8	8	17	25	
people ask before entering home	8	9	9	48	59	moved from Section II to Section 1. Also wording of question reversed in V.2000.
people ask before entering room	9	10	10	49	60	moved from Section II to Section 1. Also wording of question reversed in V.2000.
<i>consistency check</i>		11	11	12		Dropped
has friends	11	12	12	5	11	
has best friend	10	13	13	6	12	
can see friends	12	14	14	7	13	
						y/n codes were reversed prior to 2002 – should not affect outcome but may have caused data entry errors
lonely	13	15	15	9	15	
can see family	14	16	16	11	17	
know case manager	15	17	17	19	n/a	
case manager helps get what they need	17	18	18	21	29	

Question/Number	Phase VII FY05 data	Phase V- VI FY03 and FY04 data V.2002	Phase IV FY02 data V.2001	Phase III FY01 data V.2000	Phase II FY00 data V.2 (1999)	Comments
case manager asks what they want	16	19	19	22	n/a	wording change from "...what's important to you" to "...what you want"
has an advocate	18	20	20	23	31	wording change from "do you have..." to "do you know..."
received support to do new things	19	21	21	24	36	wording change from "did anyone help you learn to do something new this year" to "...reach your goals" to "...do new things you want to do"
Want more help to do new things?	20					
Happy with personal life?	21					
has transportation	22	22	22	53	63	moved from Section II to Section 1
Know how much money spent on staff?	23					
Know how much money in budget?	24					
<i>section completed</i>	25	23	23	25	37	
<i>did person understand</i>	26	24	24	26	38	
<i>did person give consistent & valid responses</i>	27	25	25	27		
Shopping	28	26	26	28	39	
Errands	29	27	27	29	40	
Entertainment	30	28	28	31	42	
eat out	31	29	29	32	43	
religious activity	32	30	31	33	44	
clubs or community orgs	33	31	31	n/a	n/a	
sports or exercise	34	32	33	30	41	added "1=yes in non-integrated setting" code in V.2001
chose home	35	33	34	36	46	wording change from "did you choose" to "who chose"
looked at more than one home	36	34	35	n/a	n/a	
chose roommate	37	35	36	37	47	
chooses home staff	38	36	37	43	52	

Question/Number	Phase VII	Phase V-	Phase IV	Phase III	Phase II	Comments
	FY05 data	VI	FY02 data	FY01 data	FY00 data	
	V.2002	FY03 and FY04 data	V.2001	V.2000	V.2 (1999)	
chooses schedule	39	37	38	38	48	wording change from "do you choose the times you do things..." to "who decides your daily schedule"
chooses free time	40	38	39	39	49	wording change from "do you choose..." to "who decides...". Also 1999 version uses phrase "for fun" instead of "in free time".
chose job	41	39	40	42	51	wording change from "did you choose" to "who chose"
looked at more than one job	42	40	41	n/a	n/a	V.1999 and V.2000 refer to job only
chose job staff	43	41	42	44	53	
chooses what to buy	44	42	43	41	56	
chose case manager	45	43	44	45	54	
mail opened without permission	46	44	45	46	57	V.2000 question more complex
can be alone with guests	47	45	46	47	58	
can use phone	48	46	47	50	61	
attended self-advocacy	49	47	48	51	n/a	added definition and response choices "n/a" and "1"
gets needed services	50	48	49	52	62	wording of question reversed in V.2000

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